NOTE TO USERS

Adductor and Abductor Spasmodic Dysphonia:

A Comparison of Quality of Life Issues for Those Receiving Botox Treatment

Dissertation

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ABSD v. ADSD/Quality of Life Issues

APPROVAL

Spasmodic Dysphonia and Quality of Life

by

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Abstract

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Spasmodic dysphonia (SD) is a chronic vocal condition that significantly affects physical, psychological, and social well being. The preponderance of studies has been with the adductor type. This survey study examined 258 participants to ascertain if there is a difference in quality of life between the multiple types, controlling for Botulinum Toxin treatment. Abductor types comprised 32.2%, adductor types comprised 51.2 %, and mixed types comprised 16.6% of the sample. An intriguing finding was that there was a significant difference in quality of life between all mixed types and adductor plus tremor and abductor plus tremor versus simple abductor and adductor spasmodic dysphonia combined (t = 2.603, df = 142, p = 0.01). However, the quality of life perceived by a person with SD did not necessarily correspond to the observed effectiveness of Botox treatment in most other cases.

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Contents

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

Introduction

Statement of the Problem

Spasmodic Dysphonia (SD) impairs the natural movement of the vocal chords, causing functional communication difficulties. While the effects of SD vary, the disease usually affects the following domains of life: "Multiple physiologic (voice quality, effort, voice dependability); personal (affective responses, changes in self-view, coping strategies); and social (physical environment, other people, participation in social roles)" (Baylor, Yorkston & Eadie, 2005, p. 395). Communication is a vital mechanism in all areas of human life, and the effects are felt in multiple domains and can have a profound effect on quality of life (QOL).

There are two main types of SD, the adductor version (ADSD) and the abductor version (ABSD). ADSD creates a strained, strangled voice with pitch breaks, and ABSD creates a hoarse, breathy voice. Another type of SD mixes the two main types together (MixedSD). In addition, each of these three types can be accompanied by a vocal tremor (TR), which causes rhythmic changes in voice ranging from giving the voice a quavering quality in more mild forms to causing temporary stoppages of voice in more severe forms. The types with tremor are ADSD with tremor (ADSDTR), ABSD with tremor (ABSDTR), and the mixed type with tremor (MixedSDTR). It will be convenient here to also indicate that ABSD with or without tremor (ABSD [TR]), ADSD with or without tremor (ADSD [TR]), and MixedSD with or without tremor (MixedSD [TR]) are terms that

will be in frequent use. One might also have a primary voice tremor alone, but this is considered a distinct condition separate from SD (Barkmeier & Case, 2000).

The same treatment of choice, injection of Botulinum Toxin (Botox) into the vocal chords, is used for all types of SD. Botox provides a temporary chemical denervation of the laryngeal nerves, blocking them from over stimulating the muscles involved with vocalization (Blitzer, Brinn & Stewart, 1998; Boutsen, Cannito, Taylor & Bender, 2002; Watts, Nye & Whurr, 2005). There is a large body of literature which supports the fact that Botox treatment significantly improves QOL for many persons with SD (Ali et al., 2006; Benninger, Gardner & Grywalski, 2001; Bhattacharyya & Tarsi, 2001; Blitzer et al., 1998; Boutsen et al., 2002; Courey et al., 2000; Futrovsky, 1992; Hogikyan, Wodchis, Spak & Kilney, 2001; Langeveld, Luteijn, Rossum, Drost & Baatenburg de Jong, 2001; Liu et al., 1998; Ludlow, Naunton, Sectary, Schulz & Hallet, 1988; Murry, Cannito & Woodson, 1994; Murry & Woodson, 1995; Rubin, Wodchis, Spak, Kilney & Hogikyan, 2004; Truong, Rontal, Rolnick, Arnold & Mistura, 1991; Watts et al., 2005; Wingate et al., 2005). Therefore, it is not possible to compare QOL of persons with SD without first controlling for Botox treatment.

The literature usually does not distinguish between the three types (ADSD, ABSD, and MixedSD) with regard to whether those types have an associated tremor. When discussing previous studies, of necessity, the terms ABSD (U), ADSD (U) and MixedSD (U) will be used, and will mean that it is unclear from the study if that type with tremor is included in that study's sample.

However, due to the prevalence of an associated TR, it is assumed that most of the larger samples did include some subjects with TR in addition to a main type. Therefore, in discussion of the literature, the ABSD (U) and ADSD (U) types will most often be used. In discussion of this particular study, the types ABSD (TR) and ADSD (TR) will be used most frequently. However, it is still assumed that most of these studies did have persons with an associated TR in their sample.

There is also a definite difference in the effectiveness of treatment between the two main ABSD (U) and ADSD (U) types (Blitzer et al., 1998; Boutsen et al., 2002). However, the corresponding difference in QOL between those who suffer from ABSD (TR) and those who suffer from ADSD (TR) who are receiving Botox injections has not been studied. A survey the membership of the National Spasmodic Dysphonia Association (NSDA) was conducted in order to study the difference in QOL between these types of SD after treatment with Botox. In a recent survey of this same NSDA sampling frame, 65% (n = 493) of the respondents were currently being treated with Botox (Feeley, 2008). The studies previously conducted which had larger sample sizes were retrospective in nature. Even with larger sample sizes, the number of patients with ABSD (U) was very small (Blitzer & Brin, 1991; Adler, Edwards & Bansberg, 1997; Murry et al., 1994; Tisch, Brake, Law, Cole & Darveniza, 2003). Because of this trend, researchers have mainly studied ADSD (U), which is the most prevalent form of SD. Using the NSDA membership as the sampling frame, a sample size large enough to study the types together exists.

Background and Significance of the Problem

Normally, there is a long delay for persons with SD between onset of symptoms and proper diagnosis (Nakanishi, 2001). One survey found that 52.6% of respondents were diagnosed between one and eight years after the onset of symptoms (Feeley, 2008). Only 22.2% were diagnosed in the first year (Feeley). This phenomenon speaks to the fact that SD is not widely known, even among professionals. In addition, until the last 25 years or so, research surrounding the etiology of SD appeared to be on the wrong track.

Early theories on SD had characterized it as caused by personality characteristics that led to a psychosomatic conversion disorder. However, research that is more recent appears to demonstrate that pre-morbid personality structure does not correlate with SD (Liu et al., 1998; Murry et al., 1994). In fact, SD is currently understood as a focal dystonia of mixed etiology, not as a psychological problem (Finitzo & Freeman, 1989).

Several studies have demonstrated the effect of SD on QOL by using standardized QOL instruments, as well as by qualitative interviewing in at least one case (Ali et al., 2006; Baylor et al., 2005; Benninger et al., 2001; Bhattacharyya & Tarsi, 2001; Courey et al., 2000; Hogikyan et al., 2001; Rubin et al., 2004). The researchers generally agree that the functional communication problems caused by SD influence the physiologic, psychological, and social domains of life (Baylor et al., 2005; Hogikyan et al., 2001). The degree to which SD affects an individual's QOL is dependent on multiple variables and the complex systemic interactions between them. These variables exist in the

interaction of the physiological, psychological/emotional, and social domains of life (Baylor et al.). While Baylor et al. propose a novel and detailed model for understanding SD in this light, most of the previous work had been done using the construct of QOL as defined by a QOL quantitative scale.

A key variable identified in the research that affects the success of treatment is whether the SD is identified as ADSD (U), which is easier to treat with Botox injections and responds to them with better results for a longer period than ABSD (U). Mixed SD (U) does not respond as well as ADSD (U) treatment either (Blitzer et al., 1998; Boutsen et al., 2002; Watts et al., 2005).

Another key variable that positively affects QOL construct measures or individual physiological, psychological, or social measures in several studies is the treatment of the person with SD by Botox injection into the vocal chords. Injection with Botox is currently the treatment of choice for SD (Blitzer et al., 1998; Boutsen et al., 2002).

SD has not only troubling physiological ramifications, but also psychological/emotional and social ones as well. QOL is significantly affected by this focal dystonia (Baylor et al., 2005; Hogikyan et al., 2001). One example of the physical problems is the quite fatiguing physical effort sometimes required just to talk (Baylor et al.). As evidence of the psychological/emotional component, those persons with SD who have not been treated effectively show significant symptoms of psychological distress that effectively treated persons do not show (Liu et al., 1998). Social functioning can be severely affected as well. As one example, there can be significant negative effects on a person's career from SD,

leading to poorer performance or a need to change professions (Smith et al., 1998). In a survey of 758 members of the National Spasmodic Dysphonia Association, more than one quarter indicated that they had changed careers because of SD (Feeley, 2008).

Given the demonstrated issues outlined above, one important area of focus for further research should be to understanding how SD influences QOL differently for those with the main two types ABSD (TR) and ADSD (TR), when those persons are being treated with Botox. This effort should include work on key variables, as well as a focus of the individual differences of the effects of the condition. Because most studies to date have been conducted with smaller sample sizes in individual clinics, an effort should also be made to use larger sample sizes in order to increase the validity of the resulting data. This study, using a larger sample size, will attempt to identify any differences in QOL between ADSD (TR) and ABSD (TR) after Botox treatment. This finding potentially could lead to further research on the differences between the ABSD (TR) and ADSD (TR) types. Collection of other key variables will also be conducted so that ancillary post hoc testing can be done to further explain the study result.

Further studies could hone in on one form of less effectively treated SD and attempt to tease out any significant physiological, psychological, or social influences of SD distinct to this sub-population. This data may present more refined forms of treatment for that type of SD. The use of QOL as a construct represents the psychological and social effects of health problems, and highlights

the contributions that the discipline of psychology needs to make in this medical field. This kind of effort could help as this field transitions from identifying psychological pathology as a causative agent to eventually using psychological knowledge to tease out the complex systemic interactions between physiologic, psychological, and social elements of the condition.

The large sample base of the NSDA provided a more comprehensive SD population representing all current types of SD, of which most are currently being treated with Botox, than the smaller sample at one medical clinic. The majority of previous studies took place in the voice clinic, and therefore provided a small sample size, with the exception of studies using retrospective designs.

One intriguing exception to the preponderance of Botox/improved QOL studies was research by Wingate et al. (2005). This study, contrary to the bulk of research, did not show a significant improvement in mean QOL scale scores after Botox treatment. The researchers studied patients over 65 years of age. Wingate et al. noted that of a small sample size of 11, three subjects had significant problems with post injection side effects. Wingate et al.'s study pointed out two key directions for future research. First, that sample sizes should be larger in order to provide more power to the result. This is especially true because Hogikyan, Wodchis, Terrel, Bradford, and Escalmado (2000) found that variance in a larger sample of the voice disorder population was within acceptable range using an F Test. Thus, the effect of confounding variables such as age and side effect can be minimized.

Second, researchers can obtain additional data for further analysis with minimal additional respondent burden without compromising respondent confidentiality, as will be outlined in the methodology section. This could include, for example, age of onset of SD, and current age, both of which could be compared in future studies against QOL data. The comparison of the current study, however, was between the types of SD and QOL, while separating out those who have and have not been receiving treatment with Botox. In fact, the group not receiving Botox injection was compared to the group receiving injection in order to confirm that this survey sample corresponded with the past research.

Research Questions/Hypotheses

Previous research has measured QOL but has not separated out the types of SD alone and in combination in QOL studies. Researchers have noted specifically that Botox works best for ADSD (U), based upon clinical measures (Blitzer et al., 1998; Boutsen et al., 2002).

Researchers have consistently studied ADSD (U) by itself because of the much larger sample sizes and the assumption that ABSD (U) and ADSD (U) are not alike in their effects on the individual. The research questions of this study asked:

Research Question 1: To what extent is there a difference in QOL as measured by the V-RQOL for ABSD (TR) and ADSD (TR) for those with Botox?

After the result from research question 1 was determined in this study, it led to ancillary post-hoc investigation of other research questions. This was done

in order to better understand the results. This inductive investigation led, in sequence, to the additional six research questions listed below.

Research Question 2: To what extent is there a difference in QOL as measured by the V-RQOL subscale scores of Physical Functioning or Social Emotional Functioning for ABSD (TR) and ADSD (TR) for those with Botox?

Research Question 3: To what extent do the demographic characteristics (duration, age, side effect, severity, and gender) of the participants significantly predict the QOL as measured by the V-RQOL?

Research Question 4: To what extent is there a difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD?

Research Question 5: To what extent is there a difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD without Botox?

Research Question 6: To what extent is there a difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR, compared to ABSD and ADSD with Botox?

Research Question 7: To what extent is there a difference in QOL as measured by the V-RQOL between ABSD and ADSD with Botox?

Based on research question 1, the hypothesis for this study is:

H1: There is a statistically significant difference in QOL as measured by the V-RQOL for ABSD (TR) and ADSD (TR) for those with Botox.

H0: There is no statistically significant difference in QOL as measured by the V-RQOL for ABSD (TR) and ADSD (TR) for those with Botox.

As indicated in the discussion above of research questions, six additional research questions were generated. Six additional hypotheses, based on the research questions, were constructed and tested after the initial hypothesis was tested. These hypotheses are:

H2: There is a statistically significant difference in QOL as measured by the V-RQOL subscale scores of Physical Functioning or Social Emotional Functioning for ABSD (TR) and ADSD (TR) for those with Botox.

H0: There is no statistically significant difference in QOL as measured by the V-RQOL subscale scores of Physical Functioning or Social Emotional Functioning for ABSD (TR) and ADSD (TR) for those with Botox.

H3: The demographic characteristics (duration, age, side effect, severity, and gender) of the participants predict the QOL as measured by the V-RQOL to a statistical significance.

H0: The demographic characteristics (duration, age, side effect, severity, and gender) of the participants do not predict the QOL as measured by the V-RQOL to a statistical significance.

H4: There is a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD.

H0: There is not a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD.

H5: There is a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD without Botox.

H0: There is not a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD without Botox.

H6: There is a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR, compared to ABSD and ADSD with Botox.

H0: There is not a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR, compared to ABSD and ADSD with Botox.

H7: There is a statistically significant difference in QOL as measured by the V-RQOL for ABSD and ADSD with Botox.

H0: There is not a statistically significant difference in QOL as measured by the V-RQOL for ABSD and ADSD with Botox.

Thus, this study will attempt to answer the seven research questions noted above by testing the seven corresponding hypotheses generated from them.

Definition of Key Terms

Abduction. An uncontrolled and irregular opening of the vocal chords characterized by phonatory breaks and excessive breathiness (Pearson & Sapienza, 2003).

Abductor SD (ABSD). Characterized by vocal folds that are abnormally apart during vocalization, creating a hoarse, whispered voice (Blitzer et al., 1998; Boutsen et al., 2002; Watts et al., 2005). This type may also have an accompanying tremor.

Adductor SD (ADSD). Characterized by vocal folds that press abnormally toward the midline, creating a strained, strangled voice with pitch breaks (Blitzer et al., 1998; Boutsen et al., 2002; Watts et al., 2005).This type may also have an accompanying tremor.

Adductor spasms. A closing off of the glottis, creating effortful stained or strangled quality to the phonation (Pearson & Sapienza, 2003).

Analysis of Variance (ANOVA). A statistical technique that analyzes variance between multiple factors to determine the significance of relationships between them.

Benzodiazepines. A class of anti-anxiety agents that can be useful as an adjunct to Botox therapy because they may help prolong the effects of Botox by relaxing muscles used during hyper-functional behaviors.

Botulinum Toxin Treatment (Botox). Currently the recognized treatment of choice for SD in the medical community. Botox works by blocking the ability of the relevant laryngeal nerves from over stimulating the muscles involved with

vocalization. This is called chemical dennervation (Blitzer et al., 1998; Boutsen et al., 2002; Watts et al., 2005).

Cascade Model. A three-stage model of grief developed to provide a model for emotional processing for those with a chronic voice disorder (de Jong et al., 2003).

Contraction and Co-contraction Reflex. Muscular adjustments that synchronize bodily movement. With SD, these become uncoordinated, creating the adductor or abductor spasms.

Conversion Disorder. A psychological diagnosis in which unacceptable emotion and impulse is represented by physical dysfunction. Part of the definitive diagnosis of this disorder is medical testing that finds no physical dysfunction.

Corticobullar Tract. A tract that runs from the cerebral cortex down to the medulla oblongata in the sub-cortex. This location is currently implicated as the center of the neurological etiology of SD.

Direct Voice Rehabilitation. A series of technique used by Morton Cooper, a speech therapist. While this technique is represented as a *cure* for SD, there is no scientific evidence to support it.

Electromyography (EMG). The use of percutaneous needles to measure the movement of muscles at rest and in contraction, an important tool in assessing and treating dystonias.

Encryption. A protected tunnel for internet communication between a computer and a website. This protection was essential to protect the privacy and

confidentiality of respondents completing the proposed survey utilized by this study.

Glottal Attack. A phenomenon where the speaker brings the vocal folds abruptly together to produce sound, making speech effortful (Voice Definitions, n.d.).

Hoarse Voice. A voice created by irregular vocal fold vibration producing a raspy, harsh, or grating sound (Voice Definitions, n.d.).

Hyperfunctional Behaviors. Compensating speech behaviors used in order to compensate for the laryngeal dysfunction. These behaviors can worsen speech after treatment with Botox, and the current practice is to address them with speech therapy, as the behaviors have become habitual.

Idiopathic Focal Dystonia. A focused movement disorder in which muscles contract and spasm involuntarily (Soland, Bhatia, & Marsden, 1996).

Laryngeal Massage. A specific technique developed for those with dysphonia which brings the voice box lower down in the throat by reducing muscle tension and repositioning the voice box.

Mixed SD. This type consists of ABSD plus ADSD or ABSD plus ADSD with a tremor.

Muscle Tension Dysphonia (MTD). The cause of dysphonia as a result of excessive muscular tension in the muscles that relate to the voice box (Voice Definitions, n.d.).

Partial thyroarytenoid myectomy. A surgical procedure for SD in which key laryngeal muscle is shaved down to a smaller size. This prevents glottal attacks

during adduction. This surgery might eventually replace SLAD-R because of its theoretical ability to retrain the nervous system.

Percutaneous electrical stimulation. Stimulation of the Vagus nerve using EMG technology to connect to the correct area to provide electrical stimulation, usually for treatment of epilepsy; however, the treatment also creates adductor spasms.

Peer Support. Used extensively around the world by the National Spasmodic Dysphonia Organization to provide psychosocial support for those with SD and their families using local groups and online discussion.

Pitch. A sound that indicates how high or low a person's voice sounds (Voice Definitions, n.d.).

Primary Voice Tremor (TR). A quavering voice that can become so severe that it causes adductor voice stoppages. It can occur alone or in combination with other types of SD.

Quality of Life (QOL). A construct that has been measured by a known Quality of Life Scale, such as the Voice Related Quality of Life Scale (Hogikyan & Sethuraman, 1999). The construct consists of measures of respondent satisfaction with the physical, psychological/emotional, and social/career domains of life.

Reverse Phonation. A speech therapy technique that has demonstrated the ability to reduce adductor spasm. However, because it relies on vocalization on the in-breath, it is very difficult to learn.

Selective Dennervation-Reinnervation (SLAD-R) surgery. Developed by Berke et al. (1999) to minimize the chance of the return of symptoms with ADSD. Adductor branches of the recurrent laryngeal nerve are severed and then reattached to cranial nerves other than the Vagus nerve that do not connect to voice production. This is thought to prevent re-growth of the laryngeal nerve.

Side effects. Additional effects of Botox treatment include hoarseness and difficulty swallowing. This hoarseness creates a temporary idiopathic vocal problem while treating the SD.

Sircle Technique. A technique that relies on thorough assessment, autogenic imagery retraining, and follow-up for a carpal tunnel like condition. It is possible that this treatment might be generalized for use with other conditions such as muscle tension dysphonia or adjunct treatment for SD.

Spasmodic Dysphonia (SD). A focal dystonia that causes physical difficulty in speech. The ramifications of this difficulty also extend to the psychological and social realms of life.

Survey Monkey. A proprietary survey website that was used for the proposed study. Respondents clicked a link in an e-mail and respond to survey items.

Vagus Nerve. A nerve that starts in the Medulla Oblongata (brain stem), extending down to the head, neck, and abdomen. The *recurrent laryngeal nerve* stems from the Vagus nerve, ultimately connecting to the laryngeal muscles that control the voice box (Bocchino & Tucker, 1978).

T-Test. A statistical test used to compare two sets of data to determine whether differences between the two sets of data are significant.

VHI (Voice Handicap Index). A QOL scale for use with a voice disorder population. In terms of breadth of health measured, VHI was defined as measuring 3 of 5 domains (physical, mental and communication) (Franic, Bramlett & Bothe, 2005).

V-RQOL (Voice Related Quality of Life Scale). A QOL scale designed specifically for use with a voice disorder population. V-ROQL measures three criteria (physical, mental/emotional and social) related to QOL (Franic et al., 2005).

Whisper. A sound that passes through the vocal folds but does not cause them to move. Many with SD can whisper without SD symptoms (Voice Definitions, n.d.).

Chapter Summary

Early theories on SD characterized it as caused by personality characteristics that led to a psychosomatic conversion disorder. However, research that is more recent appears to demonstrate that pre-morbid personality structure does not appear to correlate with SD (Liu et al., 1998).

In light of this research, SD is understood as an Idiopathic Focal Dystonia. The studies attempting to uncover etiology show that it is mixed. According to Finitzo and Freeman (1989), 50% of SD occurrences evidence multi-focal cortical lesions. Twenty-five percent have mixed sub-cortical and cortical pathology. Seven percent have sub-cortical lesions. However, a full 16% show no evidence

of cortical or sub-cortical lesions. In addition, histological studies have failed to identify any abnormality in the laryngeal nerve consistently, although they are sometimes discovered (Pearson & Sapienza, 2003). These lesions in the laryngeal nerve are thought to affect the functioning of the nerve and its ability to coordinate speech (Ludlow, Schulz, Yamashita & Deleyiannis, 1995).

The symptomatic outcome of SD is either ADSD, with a strained/strangled vocal quality, or ABSD, with a hoarse, breathy quality. MixedSD refers to the two symptom sets together. ABSD (TR), ADSD (TR), and MixedSD (TR), add a TR to the symptom set, producing a quavering voice in its mild form, but producing temporary voice stoppages in the more severe form (Blitzer et al., 1998).

These vocal symptoms create problems over the full biopsychosocial spectrum of QOL. Three domains are essentially thought to be affected: physiological, personal, and social factors (Baylor et al., 2005). There is significant agreement as to the domains, although terminology might change slightly. For example, the creators of the VHI quantify the effects of voice disorders using Physical, Emotional, and Functional subscales (Jacobson et al., 1997). The creators of the V-RQOL Scale, also used to quantify the effects of voice disorders, use Physical Functioning and Social-Emotional subscales (Hogikyan et al., 2001). Thus, SD can have significant effects on one's QOL in terms of not only physical difficulty but also the functional aspects of social and professional life, as well as psychological and emotional effects on the person.

The physical symptoms of effortful speech and fatigue with speaking associated with SD are well documented (Blitzer et al., 1998; Boutsen et al.,

2002; Ludlow et al., 1988; Truong et al., 1991; Watts et al., 2005). Psychosocial effects of SD are also well documented. These symptoms include anxiety, depression, social rejection and withdrawal, and occupational difficulty (Benninger et al., 2001; Bhattacharyya & Tarsi, 2001; Courey et al., 2000; Hogikyan et al., 2001; Rubin et al., 2004;). Please see page four for a more complete discussion of symptoms.

Currently, the treatment of choice for SD is Botox injection into the appropriate laryngeal muscle (Blitzer et al., 1998). However, this treatment is more effective with ADSD (U) than for ABSD (U) (Blitzer et al.; Boutsen et al., 2002). To this point, there does not appear to be a study that specifically measures the QOL benefit difference of Botox treatment for ADSD (TR) versus ABSD (TR) patients, despite research that shows a difference in treatment effect on symptoms.

Much is still unknown about this condition, its etiology, or its effective treatment. It is suspected that SD is a Central Nervous System disorder that affects the recurrent laryngeal nerve and therefore affects vocal production. Research has so far uncovered an idiopathic focal dystonia with a mixed neurological etiology for SD. A specific cure for the condition is unknown; therefore, treatment now focuses on symptom management. However, this treatment (Botox injection) has a variable and limited effectiveness.

As discussed above, there is an opportunity to advance knowledge of how SD affects individuals across the biopsychosocial spectrum. There are significant differences in manifestation of SD itself, and how it affects all domains of life.

Therefore, it is important to study how these differences affect QOL for those with SD. The extent that differences exist would hopefully prompt further research into the specific differences, especially as they relate to development of an effective treatment plan for each individual.

Clinical observation has noted a striking difference in the superior treatment of ADSD (U) with Botox over ABSD (U) treatment with Botox (Blitzer et al., 1998; Boutsen et al., 2002; Watts et al., 2005). Almost without exception, studies comparing treatment with Botox for ADSD (U) and ABSD (U) reveal that treatment for ADSD (U) is more effective. However, the comparison of the more comprehensive measure of QOL after Botox treatment between those with ADSD (TR) and ABSD (TR) has not yet been done.

The next chapter will review the history of research more extensively to describe the attempts to discover the etiology, effects on QOL, and best treatment choices for SD. This review confirms the need to research ADSD (TR) and ABSD (TR) QOL differences at this time in the process of researching this condition.

CHAPTER 2

Literature Review

Overview

This literature review presents the current state of research on SD and related topics, as well as the specific influence SD has on QOL for those with ADSD (U) as compared to those with ABSD (U). A review of the relevant literature will follow in order to demonstrate the current level of knowledge about SD, its etiology, treatment, and influence on the individual. Previous research strategies, and research direction, will be outlined in order to develop a rationale as to the next step to be taken in the treatment of SD.

Historical Background

Early theories characterized SD as caused by certain personality characteristics, which led to a psychosomatic conversion disorder (Bloch, 1965). This assumption is obvious because of the correlation between the significantly higher DSM Axis 1 symptoms of SD patients than the average population (Gündel, Busch, Ceballos-Baumann & Seifert, 2007). Researchers initially suspected a pre-morbid personality structure that implied a conversion reaction as a causative agent to SD. Aronson, Brown, Litin, and Pearson (1968) found that 60% of a sample of 20 SD subjects had psychoneurotic symptoms by clinical evaluation. However, the authors raised a caution flag in terms of how to interpret this correlation between psychiatric diagnosis and SD. Another important finding in this study was that SD patients also scored considerably lower on MMPI Hysteria and Hypochondriasis scales than control patients scored. In addition,

Murry et al. (2004) have found that symptoms of distress return to normal after effective Botox treatment for those with SD. The psychological correlations for SD patients are most likely due to distress over a vocally debilitating condition, not pre-morbid functioning. In addition, the interviewing psychiatrists and the researchers might have shown a predisposition toward attitudinal bias toward those with voice disorders as other studies have indicated (Amarpreet & Rochet, 2000; Blood, Mahan & Hyman, 1979).

Cannito (1991) and Murry et al. (1994) both conducted studies on SD. Cannito contended that depression, trait anxiety, state anxiety, and somatic complaints constituted four affective variables that correlated significantly with SD subjects versus controls. However, Cannito conceded that it is unknown if these variables can be correlated on the basis of reaction to a chronic disorder. Upon further study, Cannito et al. (1995), found that (utilizing the same constructs) depression, trait anxiety, state anxiety, and somatic complaints were significantly reduced one week after Botox injection, and that this effect was maintained at two months after the Botox injection.

The physiological symptoms of SD are psychologically and emotionally troubling (Cannito et al., 1995). When treated with Botox, positive vocal changes lead to positive psychological and social changes (Futrovsky, 1992; Langeveld, et al., 2001; Liu et al., 1998; Roy, Bless & Heisey, 2000). When considered in concert with the improvement in QOL scales noted earlier, the potential for reducing physiological, psychological, and social distress with proper treatment is clear. This potential also argues strongly against SD stemming from a conversion

disorder, as was once thought because of its discovery and naming by Traube in 1871 as nervous hoarseness (Pearson & Sapienza, 2003). Recent research also appears to demonstrate that pre-morbid personality structure does not appear to correlate with SD (Aronson et al., 1968; Futrovsky; Liu et al.; Murry et al., 1994; Roy et al.).

One difficulty has been that there is indeed an adductor type of dysphonia known as Muscle Tension Dysphonia (MTD), a functional voice disorder. Upon initial clinical presentation, there may be significant difficulty establishing a differential diagnosis between MTD and SD. However, the two can be distinguished by spectral analysis (Rees, Blalock, Kemp, Halum & Koufman, 2007), evaluation of phonatory air flow (Higgins, Chait & Schulte, 1999), phoniscopic evaluation (Leonard & Kendall, 1999), electromyographic study (Blitzer, Lovelace, Brin, Fahn & Fink, 1985), manipulation of the larynx (Roy, Ford & Bless, 1996) and by noting clear differences in the severity of difficulty the speaker has in comparing voiced sentences to voiceless consonant sentences and whispering (Bloch, Hirano & Gould, 1985; Mauszycki, Merrill, Gouse & Smith, 2007; Roark, Dowling, DeGroat, Watson & Schaefer, 1995). In addition, there may be difficulties that present in distinguishing between SD, MTD and a primary vocal TR. TR may be seen alone as a primary TR disorder or in combination with SD. When seen alone, primary vocal TR is considered a different condition than SD (Barkmeier et al., 2000).

As it became clearer that SD was distinct from MTD and did not show specific evidence of a functional voice disorder, researchers turned to a

physiological cause to explain SD. Initial research focused on possible damage to the recurrent laryngeal nerve. There is significant logic to this research direction. The recurrent laryngeal nerve is a branch of the Vagus nerve, and it supplies motor function and sensation to the larynx. Indeed, stimulation of the Vagus nerve leads to adductor vocal spasms (Charous, Kempster, Manders & Ristanovic, 2001; Kersig, Dejonckere, Van der Aa & Buschman, 2002). However, while there is some evidence in some cases of damage to the recurrent laryngeal nerve (Bocchino & Tucker, 1978), the results were far from conclusive (Chhetri, Vinters, Blumin & Berke, 2003; Ravits, Aronson, DeSanto & Dyck, 1979).

Research efforts turned to a focus on the cerebral cortex and sub-cortical areas. In Schaeffer's (1983) study, the brainstem was implicated in SD, with central nervous system impairment positively correlating with severity of vocal TR. Historically, similar to studies of the recurrent laryngeal nerve, studies of cortical and sub-cortical areas point to a mixed etiology. Evidence of brain injury is not always present (Aronson & Lagerlund, 1991).

Inconsistent results were also found by Devous et al. (1990). Cortical dysfunction of subjects with SD was found with one of several measuring methods; however, eight of the subjects evidenced no cortical or sub-cortical dysfunction. In fact, Finitzo and Freeman (1989), reviewing research to that point, noted that for over 50% of subjects' isolated multifocal cortical lesions can be identified, especially in the left frontal temporal cortex, medial frontal cortex, and right posterior temporal/parietal cortex. Twenty-five percent of subject had mixed

sub-cortical and cortical pathology. Seven percent had sub-cortical lesions only. For 16%, no lesions at all were identified (Finitzo & Freeman).

Due to the apparent involvement of the motor control systems in SD, much of the current speculation focuses on the sub-cortical area, especially the Basal Ganglia (Pearson & Sapienza, 2003). Oh, Park, Cho, Choi, and Jung (2004) speculated that one case of SD that had developed after use of Valproic Acid, (believed to function as a GABA transaminase inhibitor). The extrapyramidal symptoms of SD were thought to be a result of perturbations in Basal Ganglia neurotransmitters. In another case study of SD, researchers found damage to the Basal Ganglia area (Lee, Lee & Kim, 1998). In a study of blink reflex among persons with focal dystonias (including SD), increased interneuron excitability was found. Tolosa, Montserrat & Bayes (2004) theorized that this phenomenon stemmed from abnormal input, possibly from the Basal Ganglia.

The other focal dystonias are thought to have similar etiology to SD. Berardelli et al. (1998) noted on their review of the literature that all evidence of analysis of symptomatic dystonia points to a disorder of the Cortical and Basal Ganglia function. Like SD, all dystonias are characterized by an overflow of EMG activity and co-contraction of inappropriate muscles (Berardelli). Reduced spinal chord and brainstem inhibition is common to many reflex studies (Tolosa et al., 2004). In SD, as in other dystonias, there is a marked inability to inhibit inappropriate reflex activity.

However, the attempt to locate the specific dysfunction in the Basal Ganglia is far from conclusive. Hirano et al. (2001) found reduced activity in the

supplemental motor area using brain-imaging technology. This added weight to a theory of problems occurring in the entire neural network involving the cortex and sub-cortex, as opposed to one or the other. Pearson and Sapienza (2003) conclude that at present, SD as a focal dystonia is a disorder of motor circuitry and neurotransmitter function rather than structural damage to the cortex or sub-cortex regions.

Historically, the search for the etiology started with the theory that SD manifested due to a psychological conversion disorder. Research, while showing a clear correlation between Axis I anxiety and depression disorders and SD, also showed that the psychological distress subsided with effective treatment. Researchers turned to physiological factors in an attempt to understand the causality of this condition. Research has led to mixed results, with some histological studies finding problems with the recurrent laryngeal nerve, and other studies finding some problems with cortical and sub-cortical structures of the brain and associated pathways. However, no consistent finding exists.

History of Surgical Treatment

Without an accurate understanding of etiology for this condition, successful efforts to treat the condition have focused on symptom reduction instead of cure. Medical intervention began to focus on surgical treatment as it became apparent that other methods were not providing relief from the condition. Dedo (1976) began the use of surgery to relieve SD symptoms. Up to that point, older paradigms of SD treatment using speech therapy, psychotherapy, hypnotherapy, and drug therapy had proven ineffective (Barton, 1979). The initial

procedure removed a section of the recurrent laryngeal nerve, which in effect paralyzed the vocal fold on that side.

In a follow up study for patients treated from 1975 to 1982, 82% had no symptoms of spasticity (Dedo & Behlau, 1991). Aronson and DeSanto (1981) experienced a higher rate of failure with this procedure of 39%. Others attempted less radical forms of the surgery in which the nerve was crushed (Billar, Som & Lawson, 1979), or selective section of the recurrent laryngeal nerve was done, which provided a partial adductor paralysis (Carpenter, Snyder & Henley-Cohn, 1981). These less extreme methods are significantly less effective over the intermediate term, with return of symptoms in most cases (Dedo & Izdebski, 1983).

However, the search continues for a more consistently effective surgical procedure. Isshiki, Tsuji, Yamamoto, and Iizuka (2000) reported on a thyroplasty procedure, in which the cartilage of the larynx is altered to lessen the degree of vocal chord closure, but was only done with one patient, who was without symptoms at a little more than one year post-operative. An earlier but similar technique was reported as successful with 16 patients (Tucker, 1989).

Current Surgical Procedures

Emphasis has shifted to the use of Selective Innervation-Reinnervation (SLAD-R) surgery. The technique grew out of the discovery that after recurrent nerve surgery, symptoms often returned and in some cases, the nerve regenerated (Wilson, Oldring & Mueller, 1980). In the surgery, the recurrent laryngeal nerves are severed and then re-attached to a nerve not associated with

SD. The idea behind this is to prevent re-growth of the recurrent laryngeal nerve, and thus the return of SD symptoms.

The SLAD-R technique was developed by Berke et al. (1999), who found in follow-up at a minimum of twelve months and a median of thirty-six months that only one of twenty-one patients had a return of symptoms. Allegretto, Morrison, Rummage, and Lau (2003), using the SLAD-R procedure, found that 5 of 6 patients showed improvement to the point where no symptoms were noted. This SLAD-R procedure currently offers the most hope for a consistent post-operative and long lasting result.

Another surgical technique that may show future promise is partial thyroarytenoid myectomy. In this procedure, some of the vocal chord muscle is shaved in order to weaken the adductor closing during vocalization (Genack, Woo, Colton & Goyette, 1993). Koufman, Rees, Halum, and Blalock (2006) reported on the procedure with five patients, all of whom had obtained a satisfactory voice. The promise inherent in this procedure is that the reduced muscle mass may re-signal, through the recurrent laryngeal nerve, for the motor functions of the brain to re-synchronize to the lower capability of the shaved muscle fiber, but this is highly theoretical (Dr. D. Vincent, personal communication, February 28, 2008). Another possible direction for myectomy surgeries proposed by Ramacle, Plouin-Gaudon, Lawson, and Abitbol (2004) involves the use of eletrocautery in the myectomy procedure.

At this point, surgical procedures hold promise, but they are not considered the first treatment of choice for SD. Below, other non-surgical

approaches that have been attempted will be discussed. These alternative therapies are instructive as to what has been attempted, but they generally do not offer significant promise for relief of primary symptoms.

Non-surgical Alternative Strategies

As mentioned earlier, electrical stimulation of the Vagus nerve affects vocal production, creating adductor spasms (Charous et al., 2001; Kersig et al, 2002; Zalvan et al., 2003). Friedman, Toriumi, Grybauskas, and Applebaum (1989) had previously used percutaneous electrical stimulation to the recurrent laryngeal nerve, a branch of the Vagus nerve. While the researchers noted positive results, they conducted no further follow-up. This particular technique has shown more recent promise with ABSD (U). This will be discussed in more length in the current findings section (Bidus, Giovana & Ludlow, 2000).

Wood (1991) first reported on the use of acupuncture treatment for SD. This case study of a 46-year-old male with ADSD (U) was judged successful. Crevier-Buchman, Laccourreye, Papon, Nurit, and Brasnu (1997) also reported that one subject was noted to have significant clinical improvement in vocal symptoms six months after treatment. More extensive sample sizes and evaluation methods of voice using clinical evaluation and QOL scales would add weight to the results of these case studies.

In a study of the use of acupuncture treatment for SD, ten patients with ADSD (U) showed a significant improvement in VHI score (a voice related QOL scale). However, clinical voice evaluation for these patients did not show the same effect, and Lee et al. (2003) therefore could not rule out placebo effect.

While a moderate correlation exists with the VHI in terms of patient self-evaluation of severity of the voice disorder (r = 0.60), Franic et al. (2005) contend that "data are lacking regarding discriminant validity for VHI" (p. 310). It is possible that improvement might have been due to some other source than voice improvement. It would also be instructive, for example, to compare VHI scores with actual clinical voice evaluation, as done in the Lee et al. study, to compare convergent validity. Therefore, more research is needed with acupuncture treatments with SD. It may be interesting to evaluate QOL using the V-RQOL, which shows discriminant validity in comparison of voice disordered patients with normal voiced controls (Franic et al.).

Roy et al. (1996) reported on the use of manual laryngeal tension reduction via massage and manipulation of the larynx. While the technique was helpful in diagnosing the difference between muscle tension dysphonia and SD, it did not improve the primary symptoms of SD to a significant degree. However, the technique does effectively alter the posture of the larynx as well as the position of the vocal folds. In persons with MTD, this manipulation can change both articulatory and phonatory behavior for the better (Dromey, Nissen, Roy & Merrill, 2008). Continued exploration of this technique with SD patients post-Botox injection may show promise in extending the Botox benefit by reducing muscle tension associated with compensatory behaviors, which are continued even after post-Botox injection laryngeal relaxation.

Henschen and Burton (1978) reported on the use of biofeedback using EMG on the laryngeal muscles. The sample size was two. No treatment progress

was noted with the primary symptoms of SD. It is interesting to note that in contrast to these results, Maryn, De Bodt, and Van Cauwenberge (2006) found that in a literature review of studies on the use of biofeedback with all types of dysphonia (except SD), most showed success in improving vocal symptoms.

Speech therapy techniques also do not show effectiveness in the treatment of SD on their own. Harrison, Davis, Troughear, and Winkworth (1992) discuss the use of inverse phonation, otherwise called reverse phonation, in which sounds are produced during inhalation. During this abduction of the vocal folds and activation of the muscles used for the inhale, spasmodic muscular activity is minimized. While some success is noted with this technique, it is a difficult one to master and thus not useful as a consistent technique. As will be mentioned later, current thought proposes a combination of pharmacological treatment and speech therapy in combination.

Cooper (1980) contended that a form of speech therapy termed Direct Voice Rehabilitation, in contrast to traditional voice therapy that attempts to decrease hyperfunctional behaviors, would work by focusing on good vocal hygiene. Much like voice coaching, Direct Voice Rehabilitation attempts to assist the patient in finding their natural speaking pitch and range. In addition, the technique attempts to project the voice into the "mask", or the facial area, projecting energy away from the throat (Cooper, 1984). However, there is no comprehensive scholarly evidence that this technique is effective (Pearson & Sapienza, 2003).

Another attempt to relieve symptoms historically has been the use of pharmacologic therapy. Anticholinergenics, benzodiazepines, and baclofen have been tried, but no significant improvement in primary SD symptoms has been noted. These medications may be used as an adjunct to more effective treatment (NSDA, n.d.). One person with ADSD, for example, had extended voice in a desirable range by using a benzodiazepine when spasm symptoms first became noticeable (G. Smith, personal communication, 4/3/2008).

Of the alternatives to pharmacological treatment with Botox and surgery, electrical stimulation shows some promise, possibly for ABSD (U), but more study is needed with larger sample sizes. Speech therapy has been shown to extend the benefit of Botox treatment. Other techniques also may hold promise as adjuncts to more effective treatment, but none stands on its own.

Current Findings

The current theory on the etiology of SD is that it is a "disruption of neural networks involving both cortex and sub-cortex" (Pearson & Sapienze, 2003, p. 325). Most recently, Simonyan et al. (2008) reaffirmed this theory by the use of diffusion tensor imaging with 20 persons with SD and 20 controls, and then analyzing post-mortem tissue samples from one person with SD and three controls. The researcher noted an abnormality for those with SD in the area that communicates between the cerebral cortex and the medulla oblongata. They note that the corticobullar tract, which runs from the cerebral cortex down to the medulla oblongata (brain stem) and associated input and output structures, were implicated in the CNS disorder. The corticobullar tract runs through the genu of

the internal capsule. According to the authors, these brain changes could be linked to voluntary control of voice production.

In a study of the demographics of SD that covered 168 patients with SD using first degree relatives as controls, the age range for SD was found to be 13 to 71 years old, with an average age of 49 (Schweinfurth, Billate & Courey, 2002). Edwards and Bansberg (1997) found a mean age of 60 for men and 64.6 for women, in a sample of 270 clinic SD patients. According to Adler, Edwards, and Bansberg, the ration of females to males in their clinic was 3.8 to 1. Tisch et al., (2003) found in their Australian clinic that out of 169 patients, 62.1% of patients were female and 37.9% were male. The mean age at diagnosis was 56 years old, with their range of 19 to 88 years, slightly older at the bottom and older at the top of the range found by Schweinfurth et al. Blitzer and Brin (1991), in a sample of 260 patients, found a female to male ratio of 1.4 to 1. Persons with SD tend to be older, and are predominately women. With focal dystonias in general, this pattern does not hold. For example, while the ratio of women is higher with regard to spasmodic torticollis, the ratio of men is higher with regard to writer's cramp (Soland et al., 1996).

Adler et al. (1997) had 241 patients with ADSD (U) and 29 with ABSD (U) in their clinic sample. Tisch et al. (2003) noted that 89% of patients had ADSD (U), with 1.8% having the ABSD (U) variety and 4.7% having a mixed diagnosis. Blitzer and Brin (1991) found that out of their 260 patients, 32 had ABSD (U). Schweinfurth et al. (2002) contend that there are no environmental or hereditary

patterns in their data linked to SD, including family history. Most theories point to an illness, physical or psychological trauma, alone or in some combination.

The effect of SD on QOL has been demonstrated by several studies using standardized QOL instruments and by qualitative interviewing in at least one case. The researchers generally agree that the functional communication problems caused by SD influence the physiologic, psychological, and social domains of life (Baylor et al., 2005; Benninger et al., 2001; Bhattacharyya & Tarsi, 2001; Courey et al., 2000; Deary, Wilson, Carding & MacKenzie, 2003; Estella & Yiu, 2001; Hogikyan et al., 2001; Hogikyan & Sethuraman, 1999; Rubin et al., 2004; Wilson et al., 2004; Wingate et al., 2005). Perhaps this dynamic of physiologic, psychological, and emotional struggle before effective treatment with Botox led to the hypothesis of correlation of increased psychiatric symptoms and a certain pre-morbid personality structure with SD.

Key SD Quality of Life Variables

The degree to which SD affects an individual's QOL is dependent on multiple variables, and the complex systemic interactions between them (Baylor et al., 2005). The severity of SD, for example, is correlated with QOL (Gündel et al., 2007; Jones, Carding & Drinnan, 2006). As one example, not only can SD cause physical fatigue from efforts to speak throughout the day, but more severe SD can also affect a person's own sense of self and how others react to them (Amarpreet & Rochet, 2000; Blood et al., 1979).

Another key variable that positively affects QOL measures or individual physiological, psychological, or social measures in several studies is the

treatment of the person with SD by Botox injection into the vocal chords (Ali et al., 2006; Benninger et al., 2001; Bhattacharyya & Tarsi, 2001; Blitzer et al., 1998; Boutsen et al., 2002; Courey et al., 2000; Futrovsky,1992; Hogikyan et al.,,2001; Langeveld et al., 2001; Liu et al., 1998; Ludlow et al., 1988; Murry et al., 1994; Murry & Woodson,1995; Rubin et al., 2004; Truong et al., 1991; Watts et al., 2005; Wingate et al., 2005).

Holden, Yokes, Taylor, Till, and Crumley (2007) noted that the methodology of injection appears to be refining itself. Initial dosage appears to be lower than in previous years. A higher dosage can be connected to more side effects. In addition, Holden et al. note that a stable dosage is usually achieved by the third injection. Because of the variability of effect, dosage must be adjusted for each person until approximate optimal does is reached.

Lundy, Liu, Casiano, and Xue, (1997) also reported on differing methodologies for injection, dependent on desired effect. Length of response is longer with injection to target both vocal chords, but Lundy et al. noted more hoarse and breathy side effects. In a sample of 13 patients, Wingate et al. (2005) found that 3 had this side effect to the point that it significantly affected their QOL scores on the VHI. However, injection into one vocal chord decreased time of optimum benefit and decreased the hoarse and breathy side effect (Lundy et al.). In addition, Koriwchak, Nettwrville, Snowden, Courey, and Ossoff (1996) found that if side effects were troubling, a unilateral rather than bilateral injection significantly decreased reports of hoarse, breathy side effect.

Most current scenarios for best practice center on a combination of Botox and speech therapy treatment, specifically to enhance the benefit of the Botox. Murry and Woodson (1995) found, with a sample of 17 subjects receiving Botox and speech therapy and 10 controls receiving only Botox, the satisfactory amount of time subjects needed before re-treatment almost doubled with use of speech therapy. Silverman, Shrivastav, and Sapienza (2006) confirmed that Botox and effective speech therapy led to a longer, more desirable voice over just Botox or Botox and sham therapy. More studies are needed to continue to understand this extension of benefit from speech therapy techniques specifically designed to increase the benefit of Botox.

Another key variable identified in the research is whether the SD is identified as ADSD (TR) (in which vocal folds press abnormally toward the midline, creating a strained, strangled voice with pitch breaks), or ABSD (TR). This is a key variable due to a clear difference in treatment effectiveness with Botox. ADSD (U) is treated more effectively by the standard treatment of choice (Blitzer et al., 1998; Boutsen et al., 2002; Tisch et al., 2003; Watts et al., 2005).

Age is also noted as a key variable in effective treatment (Tisch et al., 2003). In addition, Wingate et al., (2005), in contrast to the preponderance of studies, did not note a significant positive change in QOL scores after injection with botulinum toxin. The 13 subjects were all over 65 years of age. Commenting on this distinction, the authors also caution that the small sample size and the side effects of botulinum toxin may have confounded the results.

As mentioned above, previous research has measured QOL, but has not separated out the types of SD alone and in combination in QOL studies. Researchers have noted specifically that Botox works best for ADSD (U) based upon clinical measures (Blitzer et al., 1998; Boutsen et al., 2002). If properly controlled for Botox treatment conditions, what is the difference in QOL, especially post-Botox, for ABSD (TR) patients as compared to ADSD (TR) patients?

Medical practitioners currently use Botox treatment for all types of SD (Blitzer et al., 1998; Boutsen et al., 2002; Watts et al., 2005). Is QOL more improved for those with ADSD (TR) than the other types upon use of Botox? If so, are other adjunct therapies needed? Do researchers need to identify other methods for treating the types which might be demonstrated as having significantly lower QOL after standard treatment? One intriguing exception to the preponderance of Botox/improved QOL studies was study by Wingate et al. (2005). The researchers studied patients over 65 years of age. However, the authors identify that their small sample size (n = 13) may have skewed the data.

Treatment with Botulinum Toxin Injection

As mentioned earlier, laryngeal injection of Botox is the current treatment of choice for all types of SD, because patients most often rate their voice as improved after treatment, and clinician observation of voice confirms this perception (Blitzer et al., 1998; Boutsen et al., 2002; Watts et al., 2005). Researchers have also clarified that voice is improved using Botox more effectively with ADSD (U) than it is with ABSD (U) (Blitzer et al.; Boutsen et al.;

Tisch et al., 2003). If ADSD (U) symptoms are demonstrably improved in most cases, even in a double blind study (Truong et al., 1991), then why would there be continuing and significant concern about assessing the negative influence of ADSD, as well as ABSD?

The side effects of Botox usually affect most patients to some degree, but can be considerable for some. Clinicians in one study considered a hoarse and breathy voice of two weeks duration or less an acceptable side effect (Beilamowicz, Stager, Badillo & Godlewski, 2002). While this is considered as optimal, some patients struggle with a breathy voice that reduces their satisfaction with the injections considerably. In one case, 3 of 13 subjects experienced this level of trouble (23%) (Wingate et al.,2005). Indeed, someone with a similar hoarse and breathy condition such as laryngitis might find their lifestyle affected with a two week bout of the illness.

In addition, the researchers noted a benefit of three months (or more) as an acceptable standard (Beilamowicz et al., 2002; Ludlow et al., 1988). As of August 2007, Blue Cross-Blue Shield of Florida allows reimbursement if Botox injections are spaced at least four months apart. In addition, patients must often schedule the next injection not at their exact moment of need, but by availability of the physician due to the necessities of scheduling. Therefore, even under an ideal circumstance the average patient may expect up to two weeks of laryngitis-like symptoms immediately after injection and perhaps a month of returning spasms before the next injection.

Botulinum Toxin Treatment and Quality of Life Differences

Despite these problems, there is a clear benefit to use of Botox for SD, not only in voice improvement, but also in QOL as measured by various QOL scales (Benninger et al., 2001; Bhattacharyya & Tarsi, 2001; Courey et al., 2000; Hogikyan et al., 2001; Rubin et al., 2004). However, QOL researchers have either distinguished an ADSD (U) population as their sample, or have not differentiated SD by type in the literature. In addition, several types of QOL scales specific to voice disorders exist, and thus a choice must be made as to which instrument to use. Several instruments exist that measure voice related QOL. Franic et al. (2005) have provided thorough analysis of the main scales that are specific to QOL and voice disorders. The authors conclude that the VHI is the better instrument for individual-level clinical decisions, while the V-RQOL is better for group level decisions. A more detailed discussion of the strengths, weaknesses, and rationale for choice of survey instrument are provided in chapter 3.

At this point it may be important to tie in the link between observable clinical measures of voice, and the use of voice related QOL scales. It is documented that voice improvement is greater for ADSD (U) than ABSD (U) with regard to observable clinical data. Blitzer et al. (1998), for example, found that with an overall sample of 900 in a retrospective analysis, ADSD (U) patients had a return to 90% of normal voice lasting an average of 15.1 weeks. ABSD (U) patients had an average improvement to 66.7% of normal voice with an average duration of 10.5 weeks. Given the previous discussion as to side effects and duration issues even in the ideal treatment group, how significant is this reduction

in vocal benefit between ABSD (U) and ADSD (U)? Despite the difference in effectiveness, the researchers conclude, "Botulinum toxin A injection of the laryngeal hyperfunctional muscles has been found over the past 12 years to be the treatment of choice to control the dystonic symptoms in most patients with spasmodic dysphonia" (p. 1435). However, no measure of the difference in QOL as a result of the unequal treatment success has appeared in the research literature.

Is there a significant difference in the QOL between ADSD (TR) patients treated with Botox and ABSD (TR) patients treated with Botox? If so, alternative treatment options might need to be developed. As an example, a currently emerging surgical procedure, selective dennervation-reinnervation surgery, is showing significant promise for the treatment of ADSD (U) (Chhetri, Mendelsohn, Blumin & Berke, 2006). Are alternative treatments for ABSD (TR) also available? As one example, Bidus et al. (2000) used percutaneous electrical stimulation of the portion of the laryngeal nerve responsible for adductor vocal movement. Ten subjects with ABSD (U) were found to have significant improvement in voice symptoms. Is this because the stimulation of this nerve pathway consisting of the vagus nerve (and the recurrent laryngeal nerve branch) creates more active adductor movement (Chavous et al., 2001; Friedman et al., 1989; Kersig et al., 2002)?

Further Analysis of Components of Quality of Life

The discipline of psychology can also continue to contribute to the ongoing research on SD. Clearly, QOL scales designed to assess the influence of voice

disorders evaluate a composite of physiological, psychological, and social factors, especially in the systemic interaction of these domains with functional impairment in communication (Franic et al., 2004; Hogikyan & Sethuraman, 1999; Jacobson et al. 1997; Wilson et al., 2004). Clinical evaluations of SD patients using DSM criteria and standardized anxiety and depression scales have been applied to this population as well, breaking down the composite of QOL into discrete emotional and social categories. These studies, however, have considered only a fraction of the entire systemic interaction of QOL influences of SD.

This documentation of improvement in psychological and social dimensions using psychometric instruments makes it clear that the physiological symptoms become psychologically and socially troubling, and when treated with Botox, positive vocal changes lead to psychological and social changes (Aronson et al., 1968; Futrovsky, 1992; Liu et al., 1998; Roy et al., 2000). When considered in concert with the improvement in QOL scales noted earlier, the potential for reducing physiological, psychological, and social distress with proper treatment is clear.

This finding is worth a more detailed look because the efforts of psychology were focused on "cure" of a functional conversion disorder until recently. Many in the field believed that SD was a functional disorder only. Murry et al. (1994) clarified Cannito's (1991) original study, which noted elevated somatic and emotional complaints from SD patients versus controls. Murry et al. found that depression and anxiety levels were significantly reduced for SD

patients both one week and two months post Botox treatment. Because depression and anxiety are also constructs of an underlying cluster of factors, this study would be an excellent clarification of statistical technique and scale use.

Thirty-two patients with SD at a voice clinic were chosen because they had received no previous Botox treatment, their symptoms had existed for over one year, they were not under psychiatric care, and they did not have any other voice disorder. Scales used included the Somatic Complaints Checklist, the State-Trait Anxiety Inventory (standardized on 1,838 working adults), and the Self-Rating of Depression Scale (SDS). The SDS was chosen by the authors because of a study which showed it to be a better predictor of a diagnosis of depression (as defined by the DSM-III in 1985) than the more well known BDI and MMPI (Murry et al., 1994). In addition, note that the State-Trait scale provides scores for both state anxiety and trait anxiety.

Each of the three scales was given to subjects pre-injection, at one week, and at two months post-injection. Of interest to this writer's study, 30 patients had ADSD (U), one had ABSD (U), and one had MixedSD. This study separated ADSD (U) from the other types as a confounding variable of several underlying factors related to QOL. Another confounding variable is that there is variability in the effect of Botox.

The authors pursued three paths statistically: To compare subjects to controls on measures of (a) Somatic complaints, (b) Anxiety, and (c) Depression. Fisher's T-Test (one tailed) was used. When there are fewer observations than

practically needed for a Chi Square Test (n = 5 for any contingency), the T-Test can provide a better measure of significance. In addition, Pearson's Product Moment Correlation Coefficients were used to see whether the present sample had an abnormal pattern of inter-correlations related to the affective variables mentioned. The researchers found statistically significant differences existed between SD subjects and controls on depression, state, and trait anxiety measures. The authors noted that somatic complaints were elevated, but not to statistical significance. In addition, the Pearson's correlation test showed a common emotional factor score of SD patients not found in controls to a significant difference.

Analysis of Variance (ANOVA) was used to measure whether there were significant changes in the affective variables post-Botox treatment. SD patients were grouped based upon pre-Botox severity level (the authors assumed that only those elevated pre-Botox would possibly change). This measured the between subjects effect. A two-way repeated-measures analysis of variance method was used. The repeated measures (the within-subjects effect) were depression and anxiety scales before and one week after. The result was that the cutoff score for the SDS scale (which is 40) provided the dividing line for severity of depression for the authors for the two-way analysis of variance. Significantly, the authors pooled the data across gender because there were not significant score differences by gender. Depressed patients improved significantly ($p < 0.05$) on each affective measure (depression, state, and trait anxiety) one week post-Botox. Depressed patients differed significantly on all affective measures pre-

Botox, but did not differ significantly post-Botox from previously non-depressed subjects. For somatic complaints, there was not a significant difference in depressed (40 or over) and non-depressed groups.

ANOVA was again used to test the stability of all affective measures from one week to two months after the treatment. In this case a one-way repeated measures ANOVA was used because severity of affective measures did not need to be controlled. There were no significant differences in the comparisons. Somatic complaints, trait anxiety, and depression were stable in score. State anxiety scores rose but not to the level of statistical significance.

Because of the multiple scaling (somatic, depression, and anxiety scales X2) the ANOVA provided a comparison of multiple factors with each other, and provided the statistical ability to separate out two different groups' pre-Botox, to eliminate diluting of the effect from those who were not depressed. Fisher's T-Test provided a better analysis than Chi Square for a data set with small values, which would make Chi Square calculations questionable. The Pearson's Correlation again provided the statistical ability to detect affective factor commonality present in those with SD missing from controls (1994).

Possible Adjunct Treatments to Botox Injection

However, it is also apparent that current Botox treatment is only "moderately" effective, and is dependent on the patient and treatment condition (Boutsen et al., 2002). As discussed earlier, even for the ideal patient and outcome, there may be gaps in optimal voice both immediately after injection and prior to the next needed injection. As mentioned earlier, ABSD (U) patients also

must contend with an average of one month less benefit than ADSD (U) patients, and more importantly, less positive symptom management even when the Botox is in the effective stage (Blitzer et al., 1998). Although methods to treat the ABSD (U) form of SD have been developed (Rontal et al., 1991), they are not as effective as treatment for ADSD (U).

It is possible that a form of treatment attempted unsuccessfully to relieve the primary symptoms of SD will provide an adjunctive treatment to current Botox therapy. Speech therapy is not considered effective by the majority of the medical community for the primary symptoms of SD, but it is considered very effective as an adjunctive treatment (Murry & Woodson, 1995). Indeed, if the Botox has minimized symptoms, perhaps speech therapy addresses the "bad habits" that persons use to compensate for the SD. Speech therapy does attempt to address the hard glottal attacks and changes in pitch and breathing pace, for example, that compensate for the vocal spasms (Murry & Woodson; Silverman et al., 2006).

MTD treatments might apply and be instructive here, because this dysphonia may be a result of poor voice hygiene as well as muscular tension. Roy et al. (1996) and Dromey et al. (2008) outlined the effectiveness of laryngeal massage and manipulation for MTD but not direct symptoms of SD. However, would it be effective as an adjunct to Botox treatment? Altman, Atkinson, and Lazarus (2005) contend that poor breath support, inappropriate low pitch, and significant cervical neck tension characterize MTD. These are similar to some of the overcompensation behaviors of a person with SD.

In a presentation at the Regional Symposium on Spasmodic Dysphonia in Tampa (2/16/2008), Freeman-Levay, M.A., CCC-SLP, outlined a strategy for post-Botox treatment that utilizes behavioral voice therapy to reduce the symptoms, compensatory behaviors, and musculoskeletal tension that comprise the process of compensating for the laryngeal spasms. Encouraging patient involvement in counseling and support groups was also a part of the treatment plan. The treatment is carried out for five distinct sessions, beginning three weeks after the Botox injection to avoid the initial side effect of breathiness and hoarseness. Both the use of speech therapy post-Botox, as well as the importance of support groups and counseling, merit further study as promising avenues to improving treatment.

Can biofeedback, which is very effective for many forms of dystonia (Maryn, De Bodt & Van Cauwenberge, 2006), but not for primary symptoms of SD (Henschen and Burton, 1978), be effective for SD in an adjunctive role? Can progressive relaxation, a relatively simple cost-effective technique to teach and to learn, be effective for SD in an adjunctive role? Research has suggested more than one effective method of relaxation and mind-body intervention (in addition to laryngeal massage, biofeedback, and progressive or deep muscle relaxation), such as hypnosis, therapeutic massage, and meditation.

Another program that might offer promise is the Sircle technique for neurophysiological retraining. A very thorough assessment is made for individuals who have developed muscle pain as the result of repetitive activity (although this is a separate condition from Carpal Tunnel Syndrome). Muscle

tension is evaluated using EMG Biofeedback, and then the patient is coached thoroughly on the techniques of autogenic imagery. The patient's critical role in the treatment is emphasized, and office visits are generally scheduled once weekly. After about 9 weeks, the sessions are cut to once or twice monthly. Anecdotal reports from a rheumatologist working with these patients are that there was a 90% success rate (G. Chartrand, personal communication, 4/8/2008).

This kind of assessment and biofeedback might prove beneficial to those with SD post-Botox or those with MTD. The autogenic relaxation training, when part of a comprehensive program as outlined above, may provide extension of Botox benefit. Relaxation training is a part of some post-Botox speech therapy (Freeman-Levay, 2008). However, what if the training were more comprehensive and geared to integrate into the patient's daily lifestyle?

Adjunct Psychological Interventions to Botox Injection

Psychological interventions may assist the person with SD in shifting from a struggle with the primary symptoms of SD to learning how to cope with the variability of Botox treatment. For example, de Jong et al. (2003) present a helpful psychological cascade model for the treatment of voice disorders. The authors adapted a three-stage model of adjustment to voice disorders from the work of Anderson (1995) with chronic back pain. This model focuses on the psychological stress around losses from before the onset of symptoms. De Jong et al.'s three-phase model views the voice disorder as causing a grief reaction with three stages: threat, falling into a pit, and finding renewal (see Table 1).

Table 1

The Psychological Cascade Model

Stages of Coping with the Voice Disorder	*Grief Characteristics*
Stage 1: Voice Disorder as a Threat	Fear of loss, search for help, isolation, depression, exhaustion
Stage 2: Falling Into the "Pit"	Surrender to the loss-Giving in without giving up.
Stage 3: Renewal	Maximum recovery in physical, functional, social, and psychological domains.

After introducing the psychological cascade model, de Jong et al. (2003) described their study of 76 teachers with a voice disorder. The researchers found that if physical and functional intervention have been attempted and the voice disorder is determined to be chronic, it is then important to review where that person is in the cascade model. Identification of current threats (Stage 1), other factors inhibiting adjustment, and mal-adaptive coping strategies should be addressed (de Jong et al.). If, as hypothesized, ABSD (TR) treatment is even less effective than ADSD (TR) treatment, this model may help a patient understand the need to accept the physical, psychological, emotional, social, and functional losses.

Based upon the model proposed by Baylor et al. (2005), we can juxtapose their domains of physiological, personal, and social QOL (and their systemic

interaction together) with the psychological cascade model and its assessment of patient coping with physical (physiological), psychological and emotional (personal), and social and functional (social) losses (see Figure 1). In their qualitative study, Baylor et al. identified common struggles that a clinician can be aware of in order to help that person move through the cascade.

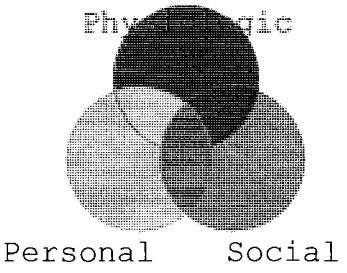

Figure 1: The biopsychosocial model of SD effects.

As one example, persons with SD must get used to a very different voice. They must deal with personal feelings like embarrassment and frustration, physiological struggles with fatigue during extended talking, and functional and social consequences on the job and in their social life (Baylor et al., 2005). Remember that those with a voice disorder are often subject to attitudinal bias (Amarpreet & Rochet, 2000; Blood et al., 1979).

Another example is a common struggle for SD patients is the knowledge that they are not being correctly represented by their voice (Baylor et al., 2005). Someone who is firm in their opinion and not intimidated may have a quavering

voice with TR, easily interpreted by others as fear. Many are forced to adapt functionally with a job change and socially by having less contact, reducing social and community roles in which speaking is key, or avoiding the telephone.

Addressing issues like these requires getting the best possible medical help, and then adapting psychological attitudes around the changes, adjusting social and functional roles in order to maximize benefit, and maintaining helpful treatments and good habits to be most comfortable physiologically. Because assessment and lifestyle counseling is not yet acknowledged in the literature for SD, this is an area that needs further exploration, especially for those who experience less effective treatment and management of troubling symptoms. While several psychological counseling theories and perspectives can come into play here, the use of the psychological cascade model provides one perspective on the usefulness of this kind of intervention. The work of de Jong et al. (2003) validated the perspective that those with persistent vocal problems often struggle in the three recognized domains of physiological symptoms, psychological issues, and social functioning of all kinds.

In a study of chronically ill patients, the use of social support was found to improve health measures of physical functioning and emotional well-being over time, regardless of age. Researchers have emphasized identifying and dealing with psychosocial problems as a key factor in maintaining the health of persons with a chronic illness (Sherbourne, Meredith, Rogers & Ware, 1992). Maija and Uchino (2008) reviewed research on social support and found a relationship between social and emotional support and health. More research is needed on

the use of support, both professional and peer-to-peer, in assisting those with SD to improve their QOL. Currently, the standard recommendation involves botulinum toxin injection and speech therapy, but does not emphasize crucial areas of psychosocial coping (Murry & Woodson, 1995; Silverman et al., 2006).

Chapter Summary

As discussed previously, no clear pre-morbid demographic variables appear to exist aside from SD patients being mostly female, older, having a higher incidence of childhood virus than the norm, and a higher incidence of essential tremor and writer's cramp. However, no specific hereditary or environmental variables emerged at a significant level to explain the etiology of SD (Schweinfurth et al., 2002).

Researchers appear to be closing in on the etiology of SD, focusing currently on the pathway between the cerebral cortex and medulla oblongata, as well as the flow of reflex activity (Simonyan et al., 2008). Still, there is no conclusive understanding of etiology. The treatment of choice currently is injection into the vocal chords with botulinum toxin accompanied by speech therapy to enhance the result of the injection (Murry and Woodson, 1995; Silverman et al., 2006). The lack of understanding of etiology directly influences the current form of favored treatment, which seeks to minimize symptoms rather than provide a cure.

SD significantly affects physiological, psychological/emotional, and social areas of life. Voice related QOL scales have been used to understand the influence of SD on QOL in a quantitative way. Hogikyan et al. (2001) have

demonstrated the effectiveness of one of these scales (the V-RQOL) in understanding the current QOL of the subjects under study.

Research to date has not yet separated the different types of SD sufficiently with regard to the effectiveness of treatment on QOL in the different diagnoses of ABSD (TR) and ADSD (TR), controlling for important variables. An opportunity exists to increase understanding of the differences between ABSD (TR) and ADSD (TR), which will raise questions about effective symptom management differences, and increase understanding about how the two differing diagnoses affect QOL. The next chapter presents the methodology of this quantitative study surveying persons with both kinds of SD while controlling for key variables that could have confounded the analysis of the data.

CHAPTER 3

Methodology

Overview

This chapter will cover the methodology of the study, beginning with a description of the research questions/hypotheses, sample population, collection method, and rationale behind using these methods. Next, important aspects of internal validity that were taken into account, such as types of variables considered and their operational definitions follow. The management of key ethical questions will then be reviewed regarding the collection, storage, and use of respondent information.

Restatement of the Problem

The study described below attempted to assess the specific influence SD has on QOL for those with ABSD (TR) as compared to those with ADSD (TR) after treatment with Botox. The literature is clear that there is a difference in the effectiveness of current treatment for ADSD (U) and ABSD (U) based upon clinical observation (Blitzer et al., 1998; Boutsen et al., 2002). It is quite possible, from reviewing the literature, that additional interventions may enhance QOL for those who are not as effectively treated with the current treatment of choice, based upon personal perception of QOL.

Statement of the Research Questions/Hypothesis

Previous research has measured QOL but has not separated out the types of SD alone and in combination in QOL studies. Researchers have noted

specifically that Botox works best for ADSD (U), based upon clinical measures (Blitzer et al., 1998; Boutsen et al., 2002).

Researchers have consistently studied ADSD (U) by itself because of the much larger sample sizes and the assumption that ABSD (U) and ADSD (U) are not alike in their effects on the individual. The research question of this study asked:

Research Question 1: To what extent is there a difference in QOL as measured by the V-RQOL for ABSD (TR) and ADSD (TR) for those with Botox?

Based upon the results obtained from the study with regard to Research Question 1, further post-hoc analysis was done to more clearly explain the result of the initial hypothesis testing. Below, six additional research questions were framed and studied in order after the result of the initial study on research question 1 was obtained. The additional six research questions asked were:

Research Question 2: To what extent is there a difference in QOL as measured by the V-RQOL subscale scores of Physical Functioning or Social Emotional Functioning for ABSD (TR) and ADSD (TR) for those with Botox?

Research Question 3: To what extent do the demographic characteristics (duration, age, side effect, severity, and gender) of the participants significantly predict the QOL as measured by the V-RQOL?

Research Question 4: To what extent is there a difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD?

Research Question 5: To what extent is there a difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD without Botox?

Research Question 6: To what extent is there a difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR, compared to ABSD and ADSD with Botox?

Research Question 7: To what extent is there a difference in QOL as measured by the V-RQOL between ABSD and ADSD with Botox?

Based on these research questions, the hypothesis for this study is:

H1: There is a statistically significant difference in QOL as measured by the V-RQOL for ABSD (TR) and ADSD (TR) for those with Botox.

H0: There is no statistically significant difference in QOL as measured by the V-RQOL for ABSD (TR) and ADSD (TR) for those with Botox.

In line with the research questions above, the post-hoc hypotheses tested below were studied in order:

H2: There is a statistically significant difference in QOL as measured by the V-RQOL subscale scores of Physical Functioning or Social Emotional Functioning for ABSD (TR) and ADSD (TR) for those with Botox.

H0: There is no statistically significant difference in QOL as measured by the V-RQOL subscale scores of Physical Functioning or Social Emotional Functioning for ABSD (TR) and ADSD (TR) for those with Botox.

H3: The demographic characteristics (duration, age, side effect, severity, and gender) of the participants predict the QOL as measured by the V-RQOL to a statistical significance.

H0: The demographic characteristics (duration, age, side effect, severity, and gender) of the participants do not predict the QOL as measured by the V-RQOL to a statistical significance.

H4: There is a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD.

H0: There is not a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD.

H5: There is a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD without Botox.

H0: There is not a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD without Botox.

H6: There is a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR, compared to ABSD and ADSD with Botox.

H0: There is not a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR, compared to ABSD and ADSD with Botox.

H7: There is a statistically significant difference in QOL as measured by the V-RQOL for ABSD and ADSD with Botox.

H0: There is not a statistically significant difference in QOL as measured by the V-RQOL for ABSD and ADSD with Botox.

The ancillary investigation was conducted after the initial hypothesis was tested in order to attempt to provide some explanation for the result. Data for variables which have been correlated in previous research with QOL, or were thought by this researcher to play a possible role in influencing QOL were also gathered. After testing the initial hypothesis, further analysis of the these key variables of age, gender, duration, severity, and side effects was done. In addition, the ancillary variable of MixedSD (TR) was later added to the analysis as well.

Description of the Research Design

The research design that was used in this study was that of a quantitative comparative design (Creswell, 1994). The reason for using the comparative research design is that it provides the researcher with the ability to determine whether there are differences in the average scores for two or more independent populations (Cozby, 2001). In the context of this study, the independent populations consisted of participants who were observed to have either ABSD

(TR) or ADSD (TR). The average scores, which were then compared with one another, were the QOL as measured by the V-RQOL survey instrument.

When the independent variables are categorical (i.e., have two or more specific categories: nominal or ordinal) the researcher can determine if differences existed between the two or more groups (Moore & McCabe, 2006). For this reason, the comparative design is appropriate because one would be able to determine if there are any differences between the two groups with respect to their QOL scores as measured by the V-RQOL.

In addition, a quantitative research design was chosen because a comparison was made between an independent variable and a dependent variable. This means that the researcher was able to assign numerical values to the predictor and outcome variables to make a comparison between the two types of variables (Creswell, 1994). The values for the independent and dependent variables were obtained by using a survey instrument that was designed to measure the QOL as well as the independent variables in the study. Therefore, the resulting variables could be assessed by using various statistical methods.

The study was designed in such a way that best efforts were taken to screen for all known intervening variables from the literature. While the variables were not initially to be analyzed in this study, except for Botox treatment, they were gathered in the case that the data required further analysis. Hogikyan et al., (2000) had previously found that voice disorder patients, uncontrolled for age, severity of the SD, and side effect of SD, could be assumed to be of equal

variance. Therefore, it was not necessary to include the variables in the initial hypothesis testing.

Operational Definition of Variables

The independent variable for the initial hypothesis test consisted of the two most frequent occurrences among the diagnoses of SD, ADSD (TR), and ABSD (TR). In addition to the two types of SD mentioned in the paragraph above, participants could be diagnosed with MixedSD, or MixedSD (TR). Those respondents who identified a primary tremor only were excluded from the study. Those with MixedSD (TR) were excluded from the initial hypothesis testing. In subsequent statistical analysis used to explain the result of testing the initial hypothesis, MixedSD (TR) was included in order to examine the data for possible intervening variables that could explain the first result.

On the survey instrument, respondent selection into the categories of ADSD (TR) and ABSD (TR) was based upon their self-report. The other type that was included on the survey was a MixedSD (TR). There was also a choice of "tremor only." This accounted for the six types found in the literature. The "tremor only" category is considered to be a different condition and was not studied. An "I don't know" category was also included on the survey to eliminate respondents who might guess at a type if forced to do so (See Appendix A, survey question 3).

The dependent variable was the mean of V-RQOL scores for either ABSD (TR) or ADSD (TR). This is how QOL was operationally defined. The mean was calculated from the algorithm provided with the scale (Hogikyan & Sethuraman,

1999). The independent variable was whether the person had ADSD (TR) or ABSD (TR). This was operationally defined by how the person designated themselves on the proposed survey. The survey included a radio button for all seven types mentioned above. The respondent could also select a "*don't know*" radio button. Those who chose "*don't know*" and also could not specify the type in the "*don't know*" section by description were eliminated. The respondents could select as many of the types as they chose.

Data regarding whether the respondent was receiving Botox treatment was collected in order to control for this significant intervening variable in the initial hypothesis. Also, data about six other possible intervening variables was collected. This data was collected in order to be able to further explain the result of the initial hypothesis if needed. These variables are defined below.

1. Botox treatment: (Botox) The most compelling variable discussed so far that affects QOL is whether or not a person has been treated with Botox injection into the vocal chords (Benninger et al., 2001; Bhattacharyya & Tarsi, 2001; Blitzer et al., 1998; Boutsen et al., 2002; Courey et al., 2000; Futrovsky, 1992; Hogikyan et al., 2001; Langeveld et al., 2001; Liu et al., 1998; Ludlow et al., 1988; Murry et al., 1994; Rubin et al., 2004; Truong et al., 1991; Watts et al., 2005). This variable was operationally defined as the respondent's identification of whether or not they are currently receiving Botox treatment.
2. Surgery: (surgery) A recent trend to emerge in the literature is surgery that is effective for treating SD in the long term (Allegretto et al., 2003;

Berke et al.,1999; Chhetri et al., 2006). Although this surgery (Laryngeal Nerve Reinnervation-Denervation), has the best documented long term outcomes, Myectomy (Koufmann et al., 2006) and Electrocautery also show promise (Ramacle et al., 2004). It was determined, however, from reviewing the literature, that if a person was receiving Botox after surgery, the surgery was not successful. Therefore, those receiving Botox who had been through surgery were counted in the data. This was operationally defined as the respondent's identification of whether or not they have ever received surgical treatment specifically for SD.

3. Side Effects of Botox, or Varying Efficacy between Patients and Treatment Conditions: (side effect) Wingate et al. (2005) studied 13 subjects with ADSD and found no significant difference after Botox injection in QOL scale score. However, the authors also argued that side effects of the Botox injections may have skewed the data with this small sample. Three of the 13 subjects had significant side effects. Side effects and a varying level of efficacy of Botox treatment between patients and between treatment conditions appear to have influenced other clinical studies of Botox effectiveness as well (Bielamowicz et al., 2002; Blitzer et al., 1998; Boutsen et al., 2002; Coureyet et al., 2000; Lundy et al., 1997). The operational definition of this variable was the respondent indicating that they have had side effects from Botox

treatment that significantly lessened the positive effects of the treatment.

4. Age: (age) The Wingate et al. (2005) study also pointed out a possible relationship between age and SD QOL. This relationship may be confounded by small sample size and by skewed data having to do with side effect and varying effectiveness, but it cannot yet be ruled out as a variable which would significantly affect result. Tisch et al. (2003) also found, in a retrospective sample of 169 clinic patients, that age potentially would be a confounding variable. This was operationally defined as the respondent's report of their chronological age in full years.
5. Gender: (gender) While the preponderance of SD patients are female (Adler et al., 1997; Blitzer & Brin, 1991; Schweinfurth et al., 2002), gender does not yet appear to be a confounding variable, either from lack of variation of benefit by gender after Botox treatment (Boutsen et al., 2002), or by neurological testing of severity (Schaeffer, 1983). The operational definition of this variable was the respondent's identification of their gender as male or female.
6. Severity of SD: (severity) Severity of SD symptoms also can be a significant intervening variable (Gundel et al., 2007; Jones et al., 2006). If so, this would change not only QOL but also possibly the treatment plan (Murry & Rosen, 2000). This variable was operationally

defined as the respondent's identification of their perception of their SD diagnosis level as mild, moderate, or severe.

7. Duration of SD: (duration) Duration does not appear to have been examined in the literature reviewed for this study. However, as indicated in the discussion of the Cascade Model, persons who have had SD longer might naturally be better adjusted psychosocially to their condition. This might lead to significant affects on QOL. This variable was operationally defined as the respondent's identification of the number of full years that they have had symptoms of the condition of SD.

In the statistical analysis of the hypothesis, treatment with Botox will be a crucial variable that will be controlled. After this analysis, the variables of duration, severity, age, side effect, and gender will be further analyzed. Surgery will not be considered to be a significant variable if the respondent is currently receiving Botox treatment, because a return to Botox treatment after surgery has been used to define an unsuccessful surgery (Chhetri, Mendelsohn, Blumin & Berke, (2006). The variable of MixedSD (TR) was also added post-hoc in order to compare differences in QOL between all types gathered in the survey.

Description of Materials and Instruments

Type of SD was measured by self-report on the survey instrument (see Survey Question 3 in Appendix A). The survey also measured whether the respondent currently received Botox treatment by respondent self-report (see Survey Question 6 in Appendix A). QOL was measured by the V-RQOL

developed by Hogikyan et al. (1999). The V-RQOL requires an algorithm calculation (see Appendix C). A V-RQOL lower score represents a lower QOL. Mean V-RQOL scores averaged in the 90s for normal controls, 70s for treated patients, and 30s for untreated patients. This includes the V-RQOL Total score, Physical Functioning score, and Social-Emotional score (1999). The V-RQOL has 10 items that were defined as measuring a Total Score, and a score for the subscale Physical Effects, and the Social-Emotional Functioning subscale. The 10 items on the V-RQOL are based on a 5-point scale that range from 1 representing "None, not at all" to 5 representing "Problem is as bad as it can be". Some of the example questions that are provided on the V-RQOL include, "I have trouble speaking loudly or being heard in specific situations" and "I avoid going out socially (because of my voice)" (see Appendix C).

Psychometric Properties of the V-RQOL

Discriminant validity for the V-RQOL was tested by comparing voice disorder groups to controls, with scores significantly lower for those with voice disorders. Convergent validity was measured by comparing V-ROQL Social-Emotional Functioning, and Physical Functioning scores and VHI total scores with a self-rating of voice quality (Hogikyan et al., 2005). Franic et al.(2005) found both the V-RQOL discriminant validity and convergent validity to be satisfactory in their analysis. It will prove important to note at this point that this convergent validity does not necessarily extend to professional observer ratings of voice quality (Lee et al., 2003).

The V-ROQL clinical data has been demonstrated as responsive with two different voice disorders (Hogikyan et al., 2001; Hogikyan et al., 2000). V-RQOL will pick up positive and negative changes in the QOL construct over time. This is significant because QOL scores can improve significantly after treatment with Botox (Courey et al., 2000; Hogikyan et al., 2001; Rubin et al., 2004). Hogikyan and Sethuraman (1999), as mentioned by Franic et al., reported a Cronbach's alpha of 0.89, and the Pearson's Product correlation was 0.93.

Hogikyan and Sethuraman (1999) contended that a relationship exists between the V-ROQL and QOL (construct validity) through a correlation between subject self-perceived voice quality rating and V-ROQL domain scores and total score at a significance level of $p < 0.001$.

Selection of Subjects

The sampling frame was the database of the NSDA. For this reason, a non-probabilistic convenience sampling method was used. This is because the information that was used for this study was taken from a pre-existing database that was established by the NSDA. The advantage of using the convenience sampling method compared to a probabilistic or random sample was that the researcher was able to obtain participants or observations for the study while spending little effort and time on selecting random participants (Cozby, 2001).

The sample was weighted more heavily toward ADSD (TR) as opposed to ABSD (TR) and Mixed (TR). The NSDA provided an e-mail list of persons belonging to the organization. Feeley (2008) conducted a survey of this

population for use in a book. Feeley used a methodology similar to the proposed distribution methodology for this study through the NSDA.

This study used the membership database of the NSDA. A survey link and invitation to participate e-mail was sent to the membership by the NSDA. The respondent clicked on the link, which went directly to the survey on the Survey Monkey website. The first page of the survey contained the informed consent document (Appendix A). If the respondent agreed to participate, a box was checked and the respondent was then sent to the survey page. The survey's first page also offered options to exit the survey without taking it, and to obtain contact information from the researcher.

The respondent completed the survey, and the data was gathered in the website in the researcher's personal account. When the study was closed, the data was analyzed. A total 395 participants agreed to the terms of the study by selecting "I have read the above information and I choose to participate in this study". The data was then downloaded in an Excel spreadsheet. The originality of the spreadsheet download was also verified by Dr. Darlene Andert, PhD, of Florida Gulf Coast University, Fort Myers, Florida, who supervised the download and kept a personal copy of the original spreadsheet. The relevant sections were transferred to SPSS software for analysis. Although 395 participants agreed to the study, sample amounts comprising valid information for each of the questions on the survey instrument was lower. Each research question eliminated respondents who did not answer the key variable survey questions associated with that hypothesis. The specific method of analysis will be described below.

In a power analysis conducted prior to the study for the initial and only proposed hypothesis (effect size = 0.85, $p < 0.05$, allocation ratio = 0.35) the smallest effective sample size could be 80 according to the G Power 3.0.10 software, with 59 in the ADSD group and 21 in the ABSD group, projecting for a one tailed t-test of independent means. The reason that most studies have not attempted to study ABSD (TR) is the difficulty with obtaining a sample size large enough in any one clinic, where sample sizes are smaller unless a retrospective review is done. Although the sampling model for this study relied on available subjects and is a non-probability sampling model, the sample size was ample for the power requirements noted. In addition, a previous researcher found that with dysphonic patients, there is not a statistically significant sample variance, even between treated and untreated patients (Hogikyan et al., 2000).

Data Collection Procedures

The survey instrument used for this study containing the V-RQOL was developed in the proprietary Survey Monkey website. An e-mail was distributed to the mailing list provided by the NSDA containing the link to the survey, asking for respondent participation (see Appendix B). The first page of the survey contained the informed consent form, and the second page contained the survey instrument (see Appendix A). The second page was only accessible by those who consented to participate in the study.

The Survey Monkey website captured each response, and collected variable and intervening variable information, as well as V-RQOL raw data. The data was collected on an Excel Spreadsheet, which was downloaded from the

Survey Monkey website. The data was sorted, and then copied into a worksheet from the Statistical Package for the Social Sciences (SPSS) software for calculation.

The survey was reviewed and tested continuously throughout development, especially to screen for appropriateness of closed or open-ended questions on any one item, clarity of item, avoidance of double barreled questions, review of whether respondents were competent to answer, making all questions relevant, making questions as short as possible, avoiding negative wording, and avoiding bias (Babbie, 1998). Pre-testing of the survey was carried out continually on a small sample of professors at Hodges University in Fort Myers, Florida who are familiar with survey research and design in order to refine the instrument. The data obtained for this study will be retained for a period of 3 years where it will then be destroyed by deleting the files from the computer.

Discussion of Data Processing

The data analysis for the study was performed in the statistical software package SPSS Version 16.0®. Descriptive statistics are used in this study in order to examine the distribution of the variables included in the study. The descriptive statistics that are used include measures of central tendency, which in this case is the mean and standard deviation of the V-RQOL scores. Other descriptive statistics that were used in the analysis are frequency tables that provide information on the number and percentage of participants by type of SD diagnosis.

Independent samples t-test. The independent samples t-test was initially used to determine whether there was a statistically significant difference between ABSD (TR) and ADSD (TR) with respect to mean V-RQOL score. By using the independent samples t-test for this purpose, the statistical significance of the difference between the two means was evaluated.

To test the initial hypothesis, the data was segregated into ABSD (TR) and ADSD (TR) groups, and was controlled for use of Botox. Then, as an ancillary analysis, the data was evaluated to determine whether these groups were significantly different on the Physical Functioning subscale or the Social-Emotional Functioning subscale.

Next, the data was segregated into analyzing the MixedSD (TR). Also included in this group, even though not a mixed diagnosis, were ABSDTR and ADSDTR. One way t-tests of independent means were performed on MixedSd, ABSDTR and ADSDTR respondents versus those with ABSD and ADSD. This first t-test used the entire sample regardless of whether or not they were receiving Botox treatment. The second t-test analyzed the two groups only if they had not received Botox. The third t-test analyzed the two groups only if they had received Botox. Based on these results, and as a check on the initial hypothesis test performed on ABSD (TR) and ADSD (TR), simple ABSD was compared to simple ADSD, removing the TR combinations used in the initial test of the hypothesis (see Tables 8, 9, 10, and 11 and Appendix F).

Multiple regression analysis. Multiple regression was used in post hoc testing to determine if several categorical independent variables (age, gender,

severity, side effect, and duration) were significant predictors of the dependent variable V-RQOL score while taking into account the other unknown independent variables in the model.

To make sure that the most parsimonious model was obtained for this analysis, a stepwise procedure was used. The stepwise regression procedure consisted of including variables in the model one at a time and then assessing their significance. This process was repeated until all five of the significant variables were included in the model. After all the significant variables were included, if it was found that a variable was no longer significant after controlling for all the other variables that were entered then this variable was removed from the model. As a result only the most significant variables were kept in the model.

Methodological Assumptions, Limitations, and Delimitations

Limitations of this study will now be described in more detail. Sampling scheme and survey methodology, choice of QOL scale and use, generalization of data to other voice disorders and other chronic conditions, and the current understanding of the etiology and effective treatment of SD will be discussed. In addition, the nature of the population under study may be an issue.

The sampling scheme used the NSDA database. Therefore, subjects self-selected due to motivation to be active in the NSDA. As one example of a confounding variable not considered, what if more motivated, resilient persons join health-based organizations and support groups for their chronic condition? In this hypothetical example, those who struggle most with the condition would not have joined NSDA, and would not be in the sample, inflating V-RQOL average

scores. Conversely, the opposite may be true. Those who are especially troubled may join for support purposes, while those who are doing well may not have such a motivation. In addition, those in the NSDA may have had SD for a longer duration than the average person. This may bias the sample because of a possible but unknown characteristic of a person with SD who would join the NSDA as opposed to one who would not (Babbie, 1998).

Another concern is that the survey was distributed by e-mail. This presupposes a competency with internet skills and an interest in responding to online surveys. Those who are not online would not participate. Although it was hoped that this distinction would not be a confounding variable, it is possible that older persons would be less likely to use the internet for communication. As discussed earlier, age was indeed a possible confounding variable for this study, again theoretically raising the V-RQOL average scores. Another age related concern had to do with the V-RQOL. One of the ten questions asks the respondent to rate if "I have trouble doing my job or practicing my profession (because of my voice)" (Hogikyan et al., 2001, p. 585). This may bias the data set by excluding those who are retired or otherwise are not employed from thoroughly completing the V-RQOL.

The V-RQOL survey itself has been analyzed to have a sufficient degree of reliability and validity, however, relationships between the construct of QOL and V-RQOL score are approximate. Another issue concerns the survey instrument itself. This proposed study will use respondent self-reports to separate subjects into the important variable categories. Respondents may be in error as

to their diagnosis, for example, the severity of their condition, and other factors. Respondent error was possible. In addition, experimenter error in collecting data and calculating results was possible.

Although one study exists that uses the V-RQOL in a sample population other than SD (vocal fold paralysis), this is the only published study using the V-RQOL outside of the SD population (Hogikyan et al., 2001). No evidence exists that these results could be generalized to other populations with a non-voice related chronic illness. However, the V-RQOL instrument itself was originally developed using a sample of 109 patients presenting at a voice clinic with a presentation of dysphonia, not specifically SD. In addition, while caution must be used in generalizing one chronic health condition to another, the V-RQOL does have a moderate (0.51) correlation to the SF-36, a general QOL instrument used to assess QOL with a diverse chronic illness population (Hogikyan & Sethuraman, 1999). In addition, as discussed earlier, the hypothesis relies on the clinical observation of voice function as a predictor of QOL as evaluated by the SD patient. This is not a known correlation (Deary et al. 2003).

Another limitation of the study was that while this study took a granular approach to diagnosis, previous studies most often identified only the simple types of SD without identifying accompanying TR as well. Therefore, when comparing the previous literature to this study, the weakness here is that is it assumed, not proven, that associated TR was included in the previous samples, just not identified.

Ethical Assurances

Each institution is required to have an Institutional Review Board in order to make sure that Federal Regulations (National Research Act of 1974) for ethical research are followed. Based on many historical problems with obtaining subject consent, undue risk to subjects, and other issues, review of the ethical standing of a study has become imperative (Ethical Research Conduct, n.d.). This section will review the methodology of the study in order to detect possible ethical concerns and resulting safeguards.

Two initial factors about the research are that the research needed human subjects and that the research covered sensitive issues such as medical diagnosis and perceptions about QOL. Therefore, it was much more practical to limit subjects to 18 years of age and older first, because it is very rare for a child to have the disorder, and second, because this limitation streamlined the informed consent procedure, especially because it would be much more difficult to obtain parental as well as child assent and consent online (Ethical Research Conduct, n.d.). Adults were also able to make a more competent choice as to whether they wish to answer personal questions or choose not to.

Because there is a mild to moderate risk of emotional upset stemming from reflection of the subject on effects of SD on their QOL, it was made clear in the informed consent document that assistance was available (see Appendix A). The lead researcher (a Licensed Social Worker in the State of Florida) made a cell phone number and e-mail address available to subjects who became upset. The subjects were also provided with contact information for the Northcentral

University Institutional Review Board and the NSDA. No subjects contacted the researcher directly for the purpose of counseling support.

Subjects were possibly motivated to assist in research because it may shed light on their condition. It was therefore important to neither overstate nor understate the effect of the research on the subject in the informed consent document. In addition, it was important to indicate that the subject may elect not to participate at any point in all or part of the study, including while reviewing the actual survey. The subject was advised that they could elect not to participate even after starting the survey (Ethical Research Conduct, n.d.).

Another crucial issue that was addressed, given the sensitivity of the information, was privacy. The NSDA provided their member e-mailing list. However, information that contained names, addresses, and e-mail addresses was not accessed directly by this researcher. The survey link and an e-mail containing informed consent and access instructions were furnished to the NSDA. No identifying information such as names or e-mail addresses of the respondents was accessed by the researcher, nor was asked for on the survey.

The survey asked for certain details about subjects' SD diagnosis and the effect it has had on their QOL. Data was collected and grouped by identifying number, which was not linked to a corresponding name or other identifying information. One step taken was to not record e-mail addresses along with survey response. The subject was provided only a web link, rather than ability to answer the survey directly on the e-mail. In addition, the IP addresses of survey respondents were eliminated from data collection as well. The Survey Monkey

site also indicates they do not collect data from any surveys on their site (Survey Monkey Security, n.d.). Therefore, neither the researcher, nor Survey Monkey, which maintains the website for the survey, had access to the identifying information about the computer where the survey response originated.

The most likely point that identifying information about the subject was in danger was while accessing the survey, where data might have been intercepted by a hacker. This threat required the use of the optional Survey Monkey secure socket layer feature. This feature provided encryption in the form of a "tunnel" through the internet, making it much more difficult for the information to be hacked by an unauthorized person (Survey Monkey Security, n.d.). Confidentiality was protected by dissemination of data to public sources only in aggregate form. All data was stored on the secure Survey Monkey site, and hard copy forms were stored in a locked file cabinet in the primary researcher's home. Due to the precautions for privacy previously mentioned, it was not judged necessary to apply for a Certificate of Confidentiality (Ethical Research Conduct, n.d.).

Because the survey was voluntary, counseling support was provided, and care was taken to give a safe access channel to the survey, there appeared to be adequate preparation in the methodology to minimize experimental risk, thus increasing the risk to benefit ratio. These steps limited the social and emotional risk. There was little apparent physical risk as opposed to other activities of daily life, and the minimal economic risk would have been from computer exposure for the subject to the internet. However, by using secure socket layer encryption, the

same protection used by personal banking sites was used, thus minimizing this risk (Ethical Research Conduct, n.d.).

Informed consent issues for respondents were addressed in the survey instrument. The informed consent document had to be accessed before the survey could be taken. This informed consent can be found in Appendix A. This document covered the crucial aspects of respondent consent to voluntary participation and cessation of participation, identification of study purpose and caution regarding possible risks. Options were provided for respondents regarding questions they had, who to contact other than the experimenter, and procedures to follow if the respondent became upset during participation in the survey process or afterwards. The text of the introductory e-mail that contained the link to the informed consent and the survey can be found in Appendix B.

In summary, several measures were taken to protect the confidentiality of respondent identifying information. The NSDA database of names was controlled only by the NSDA. All communication to study participants was channeled through the NSDA, unless consent was provided by the participant.

All responses in the survey instrument were identified by number only. As previously indicated, e-mail addresses could not be tracked because a survey web-link was provided to the respondent, and configurations in the Survey Monkey website make it possible to keep IP addresses anonymous; therefore, these Survey Monkey website features eliminate the ability to track to a particular computer. Last, because the largest danger to confidentiality is from interception

of internet traffic, a secure socket layer encryption tunnel (https) was used to connect Survey Monkey to the respondent's computer.

Any hard copy data was kept in one locked file in the lead researcher's home, and only the lead researcher had access to the key. Future dissemination of data publicly will only occur in aggregate format. Caution will be taken to only disseminate that information if there is a large enough sample to preclude the possibility of identifying any one particular response set.

Chapter Summary

This chapter outlined the methodology of delivery of the survey to test for differences in QOL among those with SD by diagnosis type. A review of the relevant literature provided a basis for the rationale used in construction of the study. The identification and operation of study variables used previous relevant studies insofar as possible. Review of instrumentation included a careful look at previous studies and their results with the instrument.

Sampling strategy and ethical considerations for respondent participation and data collection and storage were carefully considered. Survey methodology and distribution strategy were discussed. Respondent safety, privacy, confidentiality, and informed consent were reviewed for measures taken to prevent possible harm to participants, and prevention strategies to minimize the chance of harm and to maximize the benefit of the study were discussed.

Threats to the internal validity were outlined, and the ability of the results to be generalized to other conditions and situations was discussed. Included in this discussion is a listing of limitations in the study, including issues of

practicality and even what is possible and not possible to control for in preventing a confounding of the analysis of the data. In the next chapter, a review of the data obtained will be presented, discussed, and analyzed.

CHAPTER 4

Results

Overview

This chapter presents the analyses of the data as described in chapter 3. The initial question of whether there was a significant difference in the QOL (V-RQOL Total Score) between ABSD (TR) and ADSD (TR) was tested. Next, post hoc testing that was done after the testing of the initial hypothesis will be described, based upon the variables of age (age), gender (gender), amount of time that the respondent has had SD (duration), Botox side effects (Botox Rx) and SD diagnostic severity level (severity). Information will be presented that analyzes the variables mentioned with regard to V-RQOL scores.

Next, the chapter reviews a second effort post hoc effort to explain the findings from the hypothesis consisted of a review of the larger data set, which led to a significant finding outside of the variables already discussed, consisting of the difference between pure ABSD and ADSD and all other types of SD. These include MixedSD (TR), ABSD (TR), and ADSD (TR).

Demographic Description of the Sample

The average age of the entire sample was 52.18 years, with an age range from 21 to 88. The sample was primarily female (80.9%). Five percent had the mild severity level of SD, 29.5% were moderate in severity, and 24% were in the severe category. Thirty-eight percent did not know their severity level. More than half (i.e. 59.0 %) of the sample was receiving Botox treatment at the time of the survey, 63.2% of the sample at one time had experienced significant side effects

of Botox treatment, and 8.5% of the sample had been through a surgical procedure specifically for SD. The average respondent had experienced SD symptoms for 13.23 years, with a range of less than 1 year to 57 years. It took respondents an average of 5.38 years to be diagnosed with SD after symptoms started, and the time range was from less than 1 year to 50 years.

For the diagnosis summary by type presented in Table 2, the entire downloaded spreadsheet was sorted into subtotals for all diagnostic categories using the Excel subtotals command. The spreadsheet was then reviewed for multiple answers on one record. If this occurred, the most complex diagnosis was kept and all other multiple answers per record were removed from the subtotals. The most frequent type of SD for the sample was ADSD (TR) (41.9%), which was followed by ABSD (TR) (25.6%). The remaining 32.5% had some other form of SD.

Table 2

Incidence Percentage of All Types of Diagnosis

Type of SD	Number Reporting (Total *n* = 258)	Percent of Total
ABSD	66	25.6%
ADSD	108	41.9%
ABSDTR	17	6.6%
ADSDTR	24	9.3%
ABSD and ADSD	30	11.6%
ABSD and ADSD and TR	13	5.0%

Results

The first question asked in this study was whether there was a statistically significant difference in QOL as measured by the V-RQOL for ABSD (TR) and ADSD (TR) for those with Botox. It was hypothesized that there would be no difference between the two groups of participants. To determine if a significant difference existed between ABSD (TR) and ADSD (TR), an independent samples t-test was conducted analyzing the dependent variable QOL by type of SD. Since there were two independent groups in the study, Levene's test for equality of variances was conducted. The findings for this test was that the variances from each group were not significantly different from one another ($p = 0.96$). Therefore, equality of variances was assumed for the two groups. The results of the independent samples t-test showed that there was not a significant difference

between participants who had ABSD (TR) compared to participants who had ADSD (TR) in terms of their QOL ($t(125) = -0.13$, $p > 0.05$). In other words, there was no difference in the QOL of participants who were diagnosed with ABSD (TR) and participants who were diagnosed with ADSD (TR). A summary of the independent samples t-test is presented in Table 3.

Table 3

T-test for ABSD (TR) and ADSD (TR) with Botox

Test	Value
Levene's Test	F = 0.003
Levene's Test Significance	$p = 0.958$
t-test	$t = -0.129$*
t-test Significance	0.898
Standard Error Difference	4.29642

Note: See Appendix D for SPSS Output. Sample size: ABSD (TR) ($n = 41$); ADSD (TR) ($n = 86$). Mean V-RQOL by Type: (ABSD (TR) = 43.7195); (ADSD (TR) = 44.2733). *$df = 125$.

The second question asked in this study was whether there was a statistically significant difference in QOL as measured by the V-RQOL subscale scores of Physical Functioning or Social-Emotional Functioning for ABSD (TR) and ADSD (TR) for those with Botox. It was hypothesized that there would be no difference between the two groups of participants. To determine if a significant difference existed between ABSD (TR) and ADSD (TR) for those with Botox, an independent samples t-test was conducted analyzing the dependent variable

QOL by type of SD. The findings for the Levene's test of equality of variances for the Physical Functioning found that the variances from each group were not significantly different from one another ($p = 0.66$). Similarly, the variances from each group were not significantly different from one another for the Social-emotional Functioning scores ($p = 0.35$). Therefore, equality of variances was assumed for the two groups. The results of the independent samples t-test showed that there was not a significant difference between participants who had ABSD (TR) compared to participants who had ADSD (TR) in terms of their Physical Functioning scores ($t(125) = -0.45$, $p > 0.05$). In other words, there was no difference in the Physical Functioning scores of participants who were diagnosed with ABSD (TR) and participants who were diagnosed with ADSD (TR). A summary of the independent samples t-test is presented in Table 4.

Table 4

T-test of Physical Functioning Scores

Test	Value
Levene's Test	F = 0.195
Levene's Test Significance	$p = 0.659$
t-test	$t = -0.448$*
t-test Significance	$p = 0.655$
Standard Error Difference	4.29642

Note: See Appendix D for SPSS Output. Sample size: ABSD (TR) ($n = 41$); ADSD (TR) ($n = 86$). Mean V-RQOL by Type: (ABSD (TR) = 41.4364); (ADSD (TR) = 43.4109). *$df = 125$.

The results of the independent samples t-test showed that there was not a significant difference between participants who had ABSD (TR) compared to participants who had ADSD (TR) in terms of their Social-Emotional Functioning scores ($t(125) = -0.32$, $p > 0.05$). In other words, there was no difference in the Physical Functioning scores of participants who were diagnosed with ABSD (TR) and participants who were diagnosed with ADSD (TR). A summary of the independent samples t-test is presented in Table 5.

Table 5

T-test of Social-Emotional Functioning Scores

Test	Value
Levene's Test	F = 0.896
Levene's Test Significance	$p = 0.346$
t-test	$t = -0.318$*
t-test Significance	$p = 0.125$
Standard Error Difference	4.82918

Note: See Appendix D for SPSS Output. Sample size: ABSD (TR) ($n = 41$); ADSD (TR) ($n = 86$). Mean V-RQOL by Type: (ABSD (TR) = 47.1037); (ADSD (TR) = 45.5669). *$df = 125$.

The third question asked in this study was whether the demographic characteristics (duration, age, side effect, severity, and gender) of the participants significantly predict the QOL as measured by the V-RQOL to a statistical significance. It was hypothesized that the demographic characteristics

would significantly predict the QOL of the participant. To determine if any of the demographic characteristics significantly predicted the QOL a stepwise regression method was conducted. The stepwise regression procedure was conducted for participants who were receiving Botox and were ABSD (TR) and ADSD (TR). Prior to the stepwise regression analysis, the correlation between the independent variables is presented in Table 6. There was a significant positive correlation between the duration and QOL of the participants ($r = 0.21$, $p < 0.05$). There was also a significant positive correlation between the age and QOL of the participants ($r = 0.27$, $p < 0.05$). In other words, when the duration or age of the participant increased, the QOL score of the participant increased.

Table 6

Pearson's Correlations from Regression Analysis

Variable	Pearson's Correlation	Significance (One tailed)
Duration	0.212	0.040
Age	0.272	0.012
Side Effect	-0.052	0.335
Severity	-0.031	0.399
Gender	0.111	0.182

Note: Correlations were conducted between the independent variables and QOL.

The results of the stepwise regression procedure showed that there was only one independent variable that significantly predicted the QOL of the participant. This variable was the age of the participant ($p < 0.05$). In fact, the

model predicted that for every year increase in the participants age the QOL increased by 0.52 (B) units. In other words, when the age of the participant increased, the QOL increased as well. A summary of the stepwise regression model is presented in Table 7.

Table 7

Model Summary of Regression Analysis

Test	Value
Model	1
R	0.272 (Age)
R Square	0.074
Adjusted R Square	0.060
St. Error of the Estimate	23.24037
R Square Change	0.074
F Change	5.366
df 1	1
df 2	67
Sig. F Change	0.024
Durbin-Watson	2.236

Note: See Appendix D for SPSS Output. Predictors (Constant): Age; Excluded Variables: Duration, Severity, Side Effect, and Gender.

The fourth question asked in this study was whether there was a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD. It was hypothesized that there would be a significant difference between the two groups of participants. To determine if a significant difference existed between MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD, an independent samples t-test was conducted analyzing the dependent variable QOL by type of SD. The findings for the Levene's test of equality of variances found that variances from each group were significantly different from one another ($p < 0.05$). Therefore, equality of variances was not assumed for the two groups. The results of the independent samples t-test showed that there was a significant difference between participants who had ABSD and ADSD compared to participants with MixedSD (TR), ABSDTR, and ADSDTR, in terms of their QOL ($t(177.7) = 2.50$, $p < 0.05$). In other words, participants who were diagnosed with ABSD and ADSD had significantly higher QOL when compared to participants who were diagnosed with MixedSD (TR), ABSTR, and ADSDTR. A summary of the independent samples t-test is presented in Table 8.

Table 8

T-Test of MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD

Test	Value
Levene's Test	F = 5.582
Levene's Test Significance	$p = 0.019$
t-test	$t = 2.501$*
t-test Significance	$p = 0.013$
t-test Significance (one-tail)	$p = 0.0065$
Standard Error Difference	2.91165

Note: See Appendix E for SPSS Output (Equal Variances Not Assumed). Sample size: ABSD/ADSD (n = 157); MixedSD (TR), ABSDTR and ADSDTR (n = 73). Mean V-RQOL by Type: (ABSD/ADSD = 43.1051); (MixedSD (TR), ABSDTR, ADSDTR = 35.8219). *df = 177.719.

The fifth question asked in this study was whether there was a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD without Botox. It was hypothesized that there would be a significant difference between the two groups of participants. To determine if a significant difference existed between MixedSD (TR) ABSDTR, and ADSDTR versus ABSD and ADSD without Botox, an independent samples t-test was conducted analyzing the dependent variable QOL by type of SD. The findings for the Levene's test of equality of variances found that variances from each group were significantly different from one another ($p < 0.05$). Therefore, equality of variances was not assumed for the two

groups. The results of the independent samples t-test showed that there was not a significant difference between participants who had ABSD and ADSD compared to participants with MixedSD (TR), ABSDTR, and ADSDTR without Botox, in terms of their QOL ($t(65.3) = 1.00$, $p > 0.05$). In other words, participants who were diagnosed with ABSD and ADSD without Botox did not have significantly different QOL when compared to participants who were diagnosed with MixedSD (TR), ADSDTR, and ADSDTR without Botox. A summary of the independent samples t-test is presented in Table 9.

Table 9

T-Test of MixedSD (TR), ABSDTR, and ADSDTR versus ABSD and ADSD-No Botox

Test	Value
Levene's Test	F = 5.415
Levene's Test Significance	$p = 0.022$
t-test	$t = .996$*
t-test Significance	$p = 0.323$
t-test Significance (one-tail)	$p = 0.1615$
Standard Error Difference	4.09819

Note: See Appendix E for SPSS Output (Equal Variances Not Assumed). Sample size: ABSD/ADSD ($n = 97$); MixedSD (TR), ABSDTR, ADSDTR ($n = 29$). Mean V-RQOL by Type: (ABSD/ADSD = 43.7371); (MixedSD (TR), ABSDTR, ADSDTR = 39.6552). *$df = 65.319$.

The sixth question asked in this study was whether there was a statistically significant difference in QOL as measured by the V-RQOL for

MixedSD (TR), ABSDTR, and ADSDTR compared to ABSD and ADSD with Botox. It was hypothesized that there would be a significant difference between the two groups of participants. To determine if a significant difference existed between MixedSD (TR), ABSDTR, and ADSDTR types compared to ABSD and ADSD with Botox, an independent samples t-test was conducted analyzing the dependent variable QOL by type of SD. The findings for the Levene's test of equality of variances found that variances from each group were not significantly different from one another ($p = 0.28$). Therefore, equality of variances was assumed for the two groups. The results of the independent samples t-test showed that there was a significant difference between participants who had ABSD and ADSD compared to participants with MixedSD (TR), ABSDTR, and ADSDTR in terms of their QOL ($t(142) = 2.60$, $p < 0.05$). In other words, participants who were diagnosed with ABSD and ADSD with Botox did have significantly different QOL when compared to participants who were diagnosed with MixedSD (TR), ABSDTR, and ADSDTR. In fact, those who were diagnosed with ABSD and ADSD had higher QOL than participants who were diagnosed with MixedSD (TR), ABSDTR, and ADSDTR with Botox. A summary of the independent samples t-test is presented in Table 10.

Table 10

T-Test of MixedSD (TR), ABSDTR, and ADSDTR Compared to ABSD and ADSD -Botox

Test	Value
Levene's Test	F = 1.194
Levene's Test Significance	p = 0.276
t-test	t = 2.603*
t-test Significance	p = 0.010
t-test Significance (one-tail)	p = 0.005
Standard Error Difference	4.03884

Note: See Appendix E for SPSS Output (Equal Variances Not Assumed). Sample size: ABSD/ADSD (n = 103); MixedSd (TR), ABSDTR, ADSDTR (n = 41). Mean V-RQOL by Type: (ABSD/ADSD = 45.1456); (MixedSd (TR), ABSDTR, ADSDTR = 34.6341). **df* = 142.

The seventh and final question asked in this study was whether there was a statistically significant difference in QOL as measured by the V-RQOL for ABSD versus ADSD with Botox. It was hypothesized that there would be a significant difference between the two groups of participants. To determine if a significant difference existed between ABSD versus ADSD with Botox, an independent samples t-test was conducted analyzing the dependent variable QOL by type of SD. The findings for the Levene's test of equality of variances found that variances from each group were not significantly different from one another (p = 0.77). Therefore, equality of variances was assumed for the two

groups. The results of the independent samples t-test showed that there was not a significant difference between participants who had ABSD compared to participants who had ADSD in terms of their QOL ($t(101) = .28$, $p > 0.05$). In other words, participants who were diagnosed with ABSD did not have significantly different QOL when compared to participants who were diagnosed with ADSD. A summary of the independent samples t-test is presented in Table 11.

Table 11

T-test of ABSD versus ADSD with Botox

Test	Value
Levene's Test	F = .083
Levene's Test Significance	p = 0..774
t-test	t = .277*
t-test Significance	p = .782
t-test Significance (one-tail)	p = 0.391
Standard Error Difference	4.85627

Note: See Appendix E for SPSS Output (Equal Variances Not Assumed). Sample size: ABSD (n = 33); ADSD (n = 70). Mean V-RQOL by Type: (ABSD = 46.0606); (ADSD = 44.7143). *df = 101.

Chapter Summary

This chapter has focused on describing the results of data collection and statistical analysis. The null hypothesis was supported in the initial hypothesis

test, and there was no significant difference between V-RQOL scores for ABSD (TR) and ADSD (TR), or in later post-hoc testing for the Physical Effects and Social-Emotional subscales.

Other ancillary variables were then analyzed to assess their affect on V-RQOL scores, and significant findings with the available variables and data of side effects, severity, age, duration and gender were noted. Age was singled out by step-wise regression analysis as the significant variable, but the correlation was weak.

Then, a renewed look at the entire sample was conducted. A significant difference in V-RQOL mean score was found between those with MixedSD (TR), ADSDTR, and ADSDTR versus those with ABSD and ADSD. No significant difference was found in these same groups utilizing only those who were not receiving Botox. A significant difference was found in these groups when only those receiving Botox treatment were utilized. And finally, ABSD respondents were tested against ADSD respondents controlling for Botox use, and no significant difference was found in V-RQOL score.

CHAPTER 5

Discussion

This chapter presents an analysis of the data presented in chapter 4 with regard to the research questions that guided this study. The conclusions are reviewed in the context of existing research on the topics of SD and QOL. First, an introduction reviews the prominent features associated with this study and similar previous research. Next, the research questions are presented sequentially, followed by the limitations, implications for practice, and recommendations of the study.

The communication difficulties caused by SD can significantly affect speaking ability and comfort, psychological and emotional well being, and social functioning and professional effectiveness (Baylor et al., 2005). The most recent research indicates that the etiology of SD consists of a dysfunction of the neural networks of the cortex in the brain, as well as the associated neural networks of the sub-cortex in the brainstem (Simonyan et al., 2008). Although some types of surgery hold significant promise (Berke et al., 1999; Koufman et al., 2006; Ramacle et al., 2004), the current best practice treatment for SD is injection with Botox into key vocal chord muscles (Blitzer et al., 1998; Boutsen et al., 2002; Watts et al., 2005). However, despite the considerable body of knowledge and treatment skill that has amassed regarding this condition, it is evident that many people with SD still struggle with their QOL, based on the results of this study.

Many studies have shown that, in the short term at least, Botox treatment improves QOL for those with ADSD (U) (Benninger et al., 2001; Bhattacharyya &

Tarsi, 2001; Courey et al., 2000; Hogikyan et al., 2001; Rubin et al., 2004). However, research among the other simple type, ABSD (U), as well as MixedSD (U), is sparse, due to the small number of patients who appear in clinics with these types (Blitzer & Brin, 1991; Adler et al., 1997; Tisch et al., 2003).

Hogikyan et al. (2001) measured positive QOL changes in a longitudinal study for the first six injections of Botox treatment. In addition, under ideal circumstances the positive effect of Botox lasts 4.42 months (Tisch et al., 2003). Multiplying six treatments by 4.42 months would equal 26.52 months, or 2 years and 2.5 months, not counting wait time to set up appointments. This highlights a limitation of the research base, because the current study found that respondents had been having symptoms of SD for an average of 11.03 years, long past the sixth injection mark.

According to Feeley (2008), 65% of respondents with SD thought that Botox was most helpful in alleviating symptoms. The next closest choice was speech therapy at 18.5%. Recent research indicates that Botox and speech therapy make an effective combination (Murry & Woodson, 1995). Surgery, a treatment that has helped many, was only chosen by 6.2% of a sample of 758 respondents as most helpful in alleviating symptoms. It is important to note that 35% of the respondents did not choose Botox as most helpful at alleviating symptoms (Feeley). This means that one third of the respondents in that study were not using the treatment of choice at the time of the survey.

Several researchers have examined the reasons that Botox is not more effective. One issue noted in the research is that Botox is more effective for

ADSD (U) than for ABSD (U), based upon expert rating of voice (Blitzer et al., 1998; Tisch et al., 2003). Specifically, Blitzer et al., found that ADSD (U) patients had a return to 90% of normal voice lasting an average of 15.1 weeks, while ABSD (U) patients had an average improvement to 66.7% of normal voice with an average duration of 10.5 weeks. Expert rating of voice can include quantitative voice analysis, otolaryngological assessment, or computerized speech software. As stated above, ADSD (U) improves significantly when treated with Botox, although the effect much beyond 2 years of treatment in general is not known. QOL is measured by a voice related QOL scale, such as the V-RQOL instrument used in this study. Persons with SD respond to the scale based on their own internal subjective perception.

This study attempted to apply the logic that if ADSD (U) can be more easily treated with Botox, and a better result can be obtained with ADSD (U), then QOL scores should be significantly higher for ADSD (TR) than ABSD (TR) when measured in aggregate. Based upon the dearth of ABSD (U) subjects in previous studies, a high sample volume was needed in order to evaluate this difference. The NSDA sampling frame was used in order to obtain a sufficient amount of survey respondents.

Conclusions and Interpretation of Findings

This section presents the relevant data of the study with regard to the research questions and in the context of existing literature on the topics of SD and QOL. Each research question will be presented sequentially. Following the analysis, the implications of these findings are discussed.

Research question 1 asked if there is a statistically significant difference in QOL as measured by the V-RQOL for ABSD (TR) and ADSD (TR) for those receiving Botox treatment. The result of the analysis of ADSD (TR) compared to ABSD (TR) respondents currently receiving Botox treatment was first tested by including persons with an associated TR in order to increase the sample size. Analysis showed that there was no difference in the QOL of participants, (those currently receiving Botox treatment), who were diagnosed with ABSD (TR) and those who were diagnosed with ADSD (TR).

Clinical observation has indicated that ADSD is more effectively treated with Botox than ABSD based on expert-rated assessments (Blitzer et al., 1998; Boutsen et al., 2002; Tisch et al., 2003). Specifically, Blitzer et al. contended that ADSD patients had a return to 90% of normal voice lasting an average of 15.1 weeks. On the other hand, ABSD patients had an average improvement to 66.7% of normal voice with an average duration of 10.5 weeks. However, the results of the present study do not support the theory that the findings of Blitzer et al., Boutsen et al., and Tisch et al. should correlate with QOL ratings because participants with ABSD (TR) and those with ADSD (TR) had no significant differences in QOL when their respective types of SD were treated with Botox. The results of this study suggested that Botox treatment is not more effective for patients with ABSD (TR) than for patients with ADSD (TR) based upon patient perception of QOL rather than expert ratings of treatment effectiveness and voice improvement.

Research question 2 asked if there is a statistically significant difference in QOL as measured by the V-RQOL subscale scores of Physical Functioning or Social-Emotional Functioning for ABSD (TR) and ADSD (TR) for those receiving Botox treatment. The analysis of the data showed that there was no difference in the V-RQOL subscales of Physical Functioning and Social-Emotional Functioning of participants who were diagnosed with ABSD (TR) and participants who were diagnosed with ADSD (TR). This did not support the theory that significance might exist in one domain and not the other.

Hogikyan et al. (2001) suggested that SD could have significant effects on one's QOL in terms of not only physical difficulty but also the functional aspects of social and professional life, as well as psychological and emotional effects on the person. The results of this study indicate that QOL with regard to Physical Functioning and Social-Emotional Functioning may operate systemically, and thus Botox treatment perhaps addresses both simultaneously. Researchers have emphasized identifying and dealing with psychosocial problems as a key factor in maintaining the health of persons with a chronic illness (Sherbourne et al., 1992). In the context of Sherbourne et al.'s finding, the results of this study suggest that Botox may play an important role in addressing psychosocial problems by addressing physical symptoms simultaneously.

Research question 3 asked if the demographic characteristics (duration, age, side effect, severity, and gender) of the participants predict QOL as measured by the V-RQOL to a statistical significance. The analysis of the data showed that there was a weak but statistically significant positive correlation

between the age of the participant and QOL score. Wingate et al. (2005) had found that there was no statistically significant improvement in QOL for those receiving Botox over 65 years of age. In this study, age does have weak positive correlation with QOL. This apparent contradiction in result between this study and the Wingate study may be due to side effect, which had been mentioned as a possible confounding factor by Wingate et al.. The results of the present study suggested that side effect is not a confounding factor for the QOL of ABSD (TR) and ADSD (TR) participants. However, Wingate et al.'s sample size from that study was small (n = 13), and all subjects were 65 years of age or over. The sample size for this part of the current study was much larger (n=69), which may have smoothed the confounding factors of side effect, which Wingate et al. noted may have skewed their result.

Research question 4 asked if there is a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ADSDTR, and ABSDTR versus ABSD and ADSD. The results of the analysis suggested that participants who were diagnosed with ABSD and ADSD had significantly higher QOL mean scores when compared to participants who were diagnosed with MixedSD (TR), ADSDTR, and ABSDTR. During a consultation with Dr. Patrick Reidy, a Naples, Florida Ear, Nose, and Throat specialist who does Botox injections for SD, he indicated that the factor most difficult to treat in his experience was TR (personal communication, 8/28/2008). The results of this study support Dr Reidy's assertion, and suggested that the addition of TR or MixedSD significantly

decreases QOL as compared to the QOL of persons who suffer from simple ABSD or ADSD. Research questions 5 and 6 further investigated these results.

Research question 5 asked if there is a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ADSDTR, and ABSDTR versus ABSD and ADSD without Botox. The results of the data analysis indicated that participants who were diagnosed with ABSD and ADSD without Botox did not have significantly different QOL when compared to participants who were diagnosed with MixedSD (TR), ABSDTR and ADSDTR. This suggests that participants with any type of SD who are not receiving Botox treatment will have similar QOL scores. When taking into account the conclusions of research question 4 which showed a significant difference between the types, the logical next step, research question 6, provides a comparison of QOL differences between SD types receiving Botox treatment.

Research question 6, then, asked if there is a statistically significant difference in QOL as measured by the V-RQOL for MixedSD (TR), ADSDTR, and ABSDTR compared to ABSD and ADSD who are receiving Botox treatment. The results of the data analysis indicate that participants who were diagnosed with only ABSD or ADSD had higher QOL than participants who were diagnosed with MixedSD (TR), ADSDTR, and ABSDTR with Botox. Again, Dr. Reidy's comment is supported by the results, in that the addition of TR appears to be a significant detractor to quality of life among persons living with SD. However, a caveat here is that the MixedSD group, included with all tremor respondents, did contain respondents without tremor.

Last, research question 7 asked if there is a statistically significant difference in QOL as measured by the V-RQOL for ABSD versus ADSD receiving Botox treatment. TR was removed from the initial research question based upon findings of research question 6. The results of the study indicate that participants who were diagnosed with ABSD and treated with Botox did not have significantly different QOL when compared to participants who were diagnosed with ADSD who were treated with Botox. This would suggest that the findings reported by Blitzer et al. (1998), Boutsen et al. (2002), and Tisch et al. (2003) point to serious differences between expert evaluation of treatment success and patient perception of QOL. Their studies suggested that Botox injection worked more effectively for those with ADSD than it did for those with ABSD, although their studies did not take into account the possibility of TR influencing the data. Another conclusion could be that self-report measures of QOL are not directly and positively correlated with expert analysis. The following paragraphs attempt to cast the individual conclusions of the research questions in a more connected and contextual light.

The logic behind the study hypotheses stemmed from the fact that clinical observation has indicated that ADSD is more effectively treated with Botox than ABSD based on expert-rated assessments (Blitzer et al., 1998; Boutsen et al., 2002; Tisch et al., 2003). Not only is there a clinically observable effect, but there is also a clear correlation between initiation of Botox treatment and increased QOL scores on Voice Related QOL scales (Benninger et al., 2001; Bhattacharyya & Tarsi, 2001; Courey et al., 2000; Hogikyan et al., 2001; Rubin et

al., 2004). At first, it might appear that QOL is better if treatment is better. However, all that is established in these results is that QOL scores improve with Botox treatment over the short term, and that there is a clinically observable positive, if temporary, difference in voice quality, which is better and longer in duration for ADSD than for ABSD.

The key difference between clinical observation and Voice Related QOL Scales is that clinical observations of voice quality are external, and the scales rely on internal perception of QOL, which usually includes voice quality but also extends into other domains of life. Thus, many variables are at play in an internal and personal evaluation of QOL, as compared to clinical evaluation of voice quality alone. In one study of chiropractic treatment for SD, for example, improvement on a QOL scale did not match clinical observation of voice, which did not note these same improvements (Lee et al., 2003). Deary et al. (2003) contended that personal perception of voice correlated with professional evaluation of that same voice. However, while correlation between self-rating and expert rating were significant in that study ($r = 0.20$, r (squared) $= 0.04$, $p < 0.05$), this is still a weak correlation.

As discussed earlier, QOL is generally evaluated on voice related domains of physical, emotional, and social functioning. One conjecture was that the Physical Functioning or Social-Emotional Functioning V-RQOL subscales might separate out differences in QOL. As part of the post-hoc analysis, the subscales were not significantly different. In addition, while V-RQOL improvement can be dramatic after a first injection with Botox (up to 60 V-RQOL total score points),

the improvement begins to level off, though still improved, by the third injection. It would be important to know what happens over time longitudinally to V-RQOL scores of patients receiving Botox beyond six injections, the limit to the Hogikyan et al., (2001) study. Because the average duration of SD symptoms for the study participants was 11.03 years, it would be reasonable to assume that many study participants would have had many more than six injections. This duration finding also points out possible differences between patient samples in the clinical environment and the NSDA sample. This duration variable of this sample may be significantly different from that of patients who first visit a voice clinic and then are studied over the next year or two.

Another difference between this study and previous studies has to do with the diagnostic mix of the sample. Most studies, as indicated earlier, have used only ADSD (U) patients due to sampling issues. In addition, numbers reported by large clinics appear quite different from those in the NSDA sample. In combining the aggregate data of Blitzer and Brin (1991) and Adler et al. (1997), out of 521 patients, 61 (11.7%) were ABSD (U). No mention is made of MixedSD (U). Tisch et al. (2003) noted the following: 89% ADSD, 1.8% ABSD, and 4.7% mixed diagnosis.

When we compare these numbers to the NSDA sample, there is a stark difference. Out of a total response count of 258 for the question, 108 simple ADSD were recorded (41.9%), and 66 ABSD responses were recorded (25.6%). This contrasts with the 11.7% incidence of ABSD (U) noted above. Even more of a contrast, the MixedSD (TR) provided different frequency compared to the

previous studies. Twenty-four respondents (9.3%) reported ADSDTR, 17 (6.6%) reported ABSDTR, 30 (11.6%) reported MixedSD, and 13 (5.0%) noted having MixedSDTR. Between the MixedSD (TR) types alone, this accounted for 16.6% of responses alone, compared with the 4.7% noted by Tisch et al. (2003).

Limitations

One limitation of this study was the sample size. In hindsight, the first analysis in the logical chain could have been of simple ABSD and ADSD to ABSDTR and ADSDTR. However, while there were 17 ABSDTR and 24 ADSDTR in the original sample, there were only 24 in aggregate left once those who were not receiving Botox and those who did not finish the V-RQOL were removed. This number was insufficient for analysis compared to simple ABSD and ADSD. For purposes of this study, however, it would be important to note that removal of those with TR did not change the result of the ABSD and ADSD QOL comparison.

Use of the V-RQOL appeared to strengthen the study methodology; however, question number seven of the V-RQOL asks the respondent to evaluate the following statement: "I have trouble doing my job or practicing my profession because of my voice" (see Appendix C). Ten respondents with an average age of 64.9 years who were being treated with Botox did not answer question seven and thus were removed from the calculation. Those who were either retired or otherwise not working may have elected to skip the question, which might have skewed the result in the direction of higher QOL scores, based on the Wingate et al. (2005) study.

This potential skew of the regression analysis might also have affected the variables of age and duration, which were the two highest correlations when calculated against QOL. This study was also limited because the quantitative design did not allow for data to be collected on participant reconciliation to their SD conditions, which would be necessary to examine duration more extensively. For example, it would help to know where in the Psychological Cascade process proposed by de Jong et al. (2003) that the respondent was at the time of the survey.

Another limitation is that respondents chose their own medical diagnosis and severity level on the survey instrument; there was no expert evaluation involved to provide consistency across all participant responses. Because most respondents probably did not have medical training, they may not have had enough knowledge to correctly understand what they were told by their physician. In addition, another limitation inherent in this methodology is that there was no guarantee that a respondent was prevented from taking the survey more than once.

Another limitation may have been the detail of the questions asked on the survey instrument. The addition of extra data categories may have deepened the analysis. For example, if the amount of times that the respondent had been treated with Botox had been included, then this variable could have been added to the analysis. As it was, although the respondent indicated that they were currently being treated with Botox, it was not known how many times. Hogikyan et al. (2001) found that, while QOL scores at subsequent treatments were still

better than before the first treatment, they were lower than after the first injection. A longitudinal survey might have helped tease out confounding variables. In addition, the desire in survey development to keep the survey instrument burden low may have worked against the best analysis of variables by limiting the number of variables that were included.

Last, while not necessarily a weakness in itself, the constitution of the sample was quite a bit different from that of samples reported by previous clinic studies. For example, as discussed in chapter 4, this study had a much higher proportion of ABSD (TR) to ADSD (TR) than the previous studies. This can be a limitation in attempting to compare the study to previous ones with a different sample constitution.

Thus, there are certain limitations to the conclusions that can be drawn from this study. However, the large sample size and high numbers of reportedly rare types do allow for certain conclusions. Still, it would have been helpful to verify accuracy of respondent information, and to encourage respondents to answer all questions in order to increase sample size. The inclusion of more questions regarding possible confounding variables would have increased the breadth of analysis. These issues will need to be accounted for in future survey research with this population.

Implications of the Study to Practice

The conclusions section discussed the analysis of data collected from respondents with SD who are members of the NSDA. For those with SD, the current best practice treatment (Botox injection) often provides significant relief of

symptoms; however, the treatment is temporary, has side effects that affect voice negatively, and provides variable results as judged by professional observers. A variation in result has been specifically found in the treatment of ABSD (U) as compared to ADSD (U). Botox treatment for ADSD is observably better in both length of positive effect and improvement of voice. This study asked the question of whether that difference in observable improvement translated into significant differences in QOL between the two types of SD. The implications of the conclusions of the study reviewed below should be interpreted in the context of how medical professionals need to look beyond patient self-perceptions of general QOL to individual considerations to how participants feel Botox affects their specific diagnoses and why.

The sample size was adequate for the analysis. From this sample, it is clear that there is not a significant difference in personal perception of QOL between ABSD and ABSD respondents currently receiving Botox. The logical chain that begins at observable expert differences in treatment effectiveness does not end with positively correlated differences in perceived QOL. Therefore, this implies that some other unknown set of factors come into play to explain the non-significant relationship between treatment differences and QOL.

As one possibility, self-rated assessment of voice correlated weakly with expert-rated assessments in one study (Deary et al., 2003). If this relationship holds for self-perception of QOL compared with expert-rating of voice, then observable differences in treatment effectiveness are not necessarily significantly correlated with self-perception of QOL. Recent qualitative research conducted by

Baylor et al. (2007) suggested that a missing piece might be the intricacy of how Botox treatment influences each patient individually. Each patient makes their own meaning of the success and failure of their Botox treatment based on treatment factors and how these specifically influence the physical, psychological, and social areas of their unique life. This implies that the V-RQOL instrument used in this study and others may be unable to pose questions with the necessary level of subjectivity and detail to accurately assess how much Botox treatment, (and other treatments), improves the quality of life for persons living with SD. More specific QOL scaling would help in the clinical assessment of individual QOL challenges.

For example, although observable results of Botox injection for a grade school teacher might be excellent, there might be trouble making a clinic appointment for Botox injection before the beginning of each semester. That teacher's evaluation of QOL might suffer due to the need to struggle with a less optimal voice at the beginning of the semester, which is an important time to make impressions on the class. According to Baylor et al. (2007), treatment discomfort varies between individuals. As another example, then, apprehension about the medical injection procedure itself might reduce QOL perceptions. This concept of treatment burden might be more difficult for abductor than adductor patients because of the increased difficulty of locating the Botox injection effectively, increasing discomfort during injection (Patrick Reidy, M.D., Personal Communication, 9/4/2008). Yet another illustration of the point concerns the drop in V-RQOL scores over time noted by Hogikyan et al. (2001) from the first

injection to the sixth. Perceptions about QOL can change after the second and subsequent injections, even if they remain more favorable than before the first injection.

The results of this study suggested that Botox injection significantly improves QOL ABSD and ADSD patients as compared to a group consisting of all other types. This implies that Botox injection is a reliable way to treat SD, and may be a strong foundation for other types of SD treatment. Murry and Woodson (1995) and Silverman et al. (2006) pointed to another dynamic: change in speech behavior after Botox injection. Speech therapy after Botox can almost double the length of Botox effectiveness, focusing on compensatory speech behaviors and musculoskeletal tension. The dynamic behind this needs further investigation. It is possible, for example that this change in behaviors can be extended as well. Perhaps neurophysiological training using thorough assessment and biofeedback techniques might enhance the speech behavior changes observed in speech therapy after Botox injection. The Sircle technique, discussed in the literature review, is one innovative example of neurophysiological retraining. It does not appear that this technique has been specifically studied with SD. Adding weight to this idea, Maryn et al. (2006) found that biofeedback applied to other types of dysphonia often showed success in the form of improved vocal symptoms. They key here is intervene to change vocal behaviors and neuromuscular patterns after Botox injection, not before.

Recommendations for Future Research

Perhaps the most compelling finding in this study came from post-hoc testing used to explain the result of the initial hypothesis. The group of SD respondents diagnosed with MixedSD (TR), ADSDTR, and ABSDTR had significantly lower V-RQOL scores than simple ABSD and ADSD respondents combined, controlled by inclusion of only those currently receiving Botox treatment. This relationship will need further definition. It is possible that the key variable is the inclusion of TR, which is not effectively treated with Botox; it is also possible that the key variable is the MixedSD diagnosis, which might create more difficulty in treatment. Conversely, the key variable might be as yet unnamed or may be a combination of factors.

In addition, much more needs to be known about the variables that contribute to QOL. Certainly, Botox treatment is the primary variable affecting QOL that is known at this time, either on its own or in concert with focused speech therapy. This study did not determine how long the respondent had been using Botox, just that they were using it at the time of survey completion. More work needs to be done with longitudinal studies of QOL and Botox use over longer periods of time, both with and without focused speech therapy, or using other types of neuromuscular retraining. It would be important to note here that research continues into the key area of Botox injection method, in order to increase benefit and reduce side effects (Beilamowicz et al., 2002). However, more studies are needed in this regard with the types that show up more rarely to the clinic, such as ABSD or a particular type with TR. The preponderance of

research has been done on the type of SD that responds best to Botox (ADSD (U)).

We might assume that our survey respondent size was large enough that the ABSD (TR) comparison to ADSD (TR) QOL was not muted or amplified by a skewed sample. Thus, this result can begin to shift the perspective first taken in this study. It is intriguing that despite the additional treatment burden and decreased effectiveness of Botox treatment for ABSD, respondents with ABSD and ADSD make meaning of their QOL in roughly the same way. This leads to the question of how those who score higher on the V-RQOL make meaning out of their life with SD. There would be a mix of internal psychological factors that could be studied in order to form a template of the thoughts, emotions, and behaviors of someone who copes well with SD. One possible confounding factor in this regard that was not studied involved the participation of the respondent in support groups, either in person or online. The NSDA membership has access to this kind of support. The qualitative work of Baylor et al. (2005) and Baylor et al. (2007) deepened the field's understanding of individual and subjective factors within the physical, psychological, and social domains of QOL. One effective method would be to alternate qualitative studies with quantitative studies utilizing larger sample sizes based on the qualitative findings. This methodology might expose more factors that affect QOL. It also might help direct the content of future scales designed to tap into individual differences in perception and needs.

A statistically significant finding existed between MixedSD (TR), ABSDTR, and ADSDTR versus the simple ABSD plus the ADSD types receiving Botox

treatment. However, when Botox was removed as a variable, the result became not significant. This relationship needs further exploration in order to tease out the exact meaning of these findings. At this point, it is unknown if the variable of added TR might be the significant variable in QOL with Botox treatment, or if it is the MixedSD type itself that is the key. The combination of ABSDTR and ADSDTR who receive Botox drops down to 14 in this dataset, making comparison of those with TR to those without difficult. Thus, as Wingate et al. (2005) found, a small sample like this left the result vulnerable to confounding variables. However, some factor within the types of SD diagnoses does appear to be related to QOL perception. Further work with a larger data sample might tease out this relationship.

Maija and Uchino (2008) reviewed the current state of research on social support, and found a relationship between social and emotional support and health. Sherbourne et al. (1992) found that social support increased the physical health and emotional well being of chronically ill people. Barry (2000) noted that in a regression analysis of factors related to chronic illness and social support, that social support is related to emotional functioning but not to physical functioning. Futrovsky (1992) found that the number of social supports that a person with SD had correlated with social adjustment, a construct which might form a significant part of QOL. A future study could examine the NSDA sampling frame and analyze support group membership QOL compared to those who are not in a support group. In order to understand the implications of social support, the V-RQOL or other instrument that has a Physical subscale and a Social-

Emotional subscale could be used. If the previous findings hold true, then further factors related to the cognitive-emotional-behavioral template mentioned in the last paragraph could be studied further. In addition, because only 6.3% of the NSDA membership attends a support group, and only 6.2% participate in online SD forums, demonstrated positive result from support group membership could help increase membership (Feeley, 2008).

One of the crucial functions of a support group could be to facilitate the emotional acceptance of the persistent voice problems associated with SD through awareness of the grief reaction. De Jong et al. (2003) contended that perhaps the futile emotional struggle involved with not accepting a voice disorder becomes problematic. In describing the Psychological Cascade Model of recovery from chronic illness, they noted from their study of 76 teachers with chronic, persistent voice problems that most (71%) were stuck in Stage one, when the person with the voice disorder experiences the illness as a threat. Subjects at this stage had more inadequate coping strategies and more serious voice complaints.

Stage two, reached by only 16%, is called the Pit. This is characterized by surrender to the loss. Surrender in this case is has a positive connotation, where the illness is accepted and incorporated into one's life view, without necessarily giving in to it. Much of the depression, anxiety, and other undesirable psychological states ease significantly in this second phase. The third stage is characterized by renewal and recovery. This third stage goes beyond acceptance

to a new life that accepts the limitations imposed by the voice disorder, yet seeks to maximize opportunities and QOL.

Although the variable of duration in this study showed only a weak correlation, perhaps specific groups of SD diagnoses that show the most persistent problems might show a higher correlation with low QOL in a future study. If so, any group with a high correlation with low QOL scores might be studied using the model and methodology presented by de Jong et al. in order to detect Psychological Cascade phase as matched against QOL score. Based on the results of this study, it would also be difficult to ignore age as a potential variable in how a person becomes reconciled to a lifelong physical problem like SD.

Another research tactic might be to conduct domain specific research in order to understand the dynamics of the interaction of the person, SD, and that domain. For example, Feeley (2008) noted the majority of respondents felt that they had been discriminated against in some way in the work environment. The highest choice was being "viewed as weak" (14.9%), then "hiring difficulties" (12.3%) and "job loss" (12.3%). Social discrimination (9.8%) and "limited opportunities for promotions (7.7%) also figured prominently. Further studies should investigate how the variable of job discrimination may influence QOL perceptions in persons with SD.

Alternatively, another domain specific research effort could center on the effect of SD on marital relationships in order to assess its effect on QOL. Measurement of marital satisfaction on a standardized scale such as the

ENRICH Marital Satisfaction Scale would provide a reliable, and valid measure of marital satisfaction with a low response burden at 15 items (Flowers & Olson, 1993). Marital satisfaction scale scores of married persons with SD could be compared against a control group of married persons.

Based upon the results of this study, it is also recommended that qualitative studies be performed with participant groups similar to those of this study in order to obtain more detailed information about how SD impacts QOL in a more open ended format. This study points out the need to discover more known factors that affect QOL. The value of such qualitative research would be that it takes a more post-modern view than this current study, and focuses on the unique internal experience of each person among many complicated relationships between the person, their life domains, and the treatment and its effects. In other words, merely noting that two patients in a clinic have achieved the same expert rating in voice improvement does not connect directly to equivalent internal experiences about the result. When the dynamics of person, biopsychosocial domains, and treatment interactions are considered, the number of possible factors grows exponentially and appears to be best considered in each individual case or with small sample sizes (e.g., focus groups).

Clinical studies of other alternative treatments to this point appear have attempted to cure the condition or improve SD symptoms as a primary treatment. Another area of clinical study might be to attempt previously studied adjunct treatments in concert with Botox, rather than attempting to take on the full force of the spasms. For example, Roy et al. (1996) and Dromey et al. (2008) identified

the benefits of laryngeal massage with muscle tension dysphonia. It is possible that this might help with some of the same behaviors that speech therapy does, because the compensating speech behaviors of someone with SD are similar to the muscle tension disorder that laryngeal massage treats.

Summary

In summary, this study presents more questions than it answers. More needs to be known about the effectiveness of Botox injection with all types of diagnosis. Questions need to be answered about what happens to QOL over time under Botox treatment. The similar QOL scores between ABSD (TR) and ADSD (TR) respondents have implications in terms of expert measurements versus personal perception in physical, psychological, and social domains. Social support mechanisms and their role in improving QOL with SD need further study. Further study of adjunct treatments to Botox is another promising avenue of inquiry. While this study shows that expert assessment of vocal quality does not correlate with personal perception of QOL, the *bridge* between the two perceptions that would make them link logically is compelling. Perhaps most importantly from a psychological perspective, further study of how persons with SD make meaning of their QOL could provide a template of cognitive, emotional, and behavioral attitudes which lead to a higher personal evaluation of QOL.

This study found the original null hypothesis to be true, that there is no difference in QOL between those with ABSD (TR) receiving Botox and those with ADSD (TR) receiving Botox. This finding highlights that there are factors other than degree of effectiveness of treatment that influence QOL. More research

needs to be done on the factors located in this gap between expert rating of treatment effectiveness and patient rating of life effectiveness. A bridge is needed to connect the inner world of the patient and the unique social environment they inhabit to the outer expert evaluation process.

Although ABSD and ADSD QOL scores were not significantly different, these two types combined have a significantly higher QOL when compared against MixedSD (TR) in combination along with ABSDTR and ADSDTR, when treated for Botox. While not the origional focus of this study, this finding deserves further attention. Based upon the result above and the lack of information on treating MixedSD (TR), as well as ABSD (TR) and ADSD (TR), it is not known if the key variable in this case will prove to be treatment effectiveness with MixedSD (TR), and ABSD (TR) and ADSD (TR), or something else entirely. It is worthy of note that the two pure types have a higher mean QOL score than any other type.

Perhaps most important, however, those factors in the gap for ABSD and ADSD do not necessarily correlate with treatment effectiveness, but will somehow correlate with other intriguing factors that affect personal perception of their physical functioning and social-emotional functioning. Research efforts, and eventually treatment efforts, may someday be comprised of a multi-disciplinary team focused not only on body, but also on mind and psychosocial support.

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Appendix A: THE SURVEY INSTRUMENT

1. At the bottom of this page you will be asked to indicate that you would either like to participate in the survey, NOT participate in the survey, or that you would like further information about the survey before continuing.

1.) If you choose not to participate you will be directed away from the survey page. You may then close your browser.

2.) If you wish to obtain more information you will be directed to a page that will include contact information for the lead researcher of this study, so that you may ask your question.

3.) If you choose to participate, you will be directed to the survey page where you will then be asked various questions about your SD and how it affects you. When you are done with the survey the results will be stored and collected with all other participants.

If you do not wish to answer a question, you may leave it blank.

Consent to participate: By checking the agreement to participate checkbox below, I am giving my consent to participate in this study. I agree to participate after thoroughly reading the above material on this page. If I have any questions about participation in the study, they have already been answered. I also agree that I am over 18 years of age.

CHECK ONLY 1 BOX BELOW

- ☐ Yes, I have read the above information and I choose to participate in this study.
- ☐ No, I do not want to participate in this study at this time.
- ☐ I have questions or require more information about this study.

2. Demographic Information

1. What is your gender?

- ◯ Male
- ◯ Female

2. What is your age?

3. What type of Spasmodic Dysphonia (SD) do you have?

- ☐ Abductor SD
- ☐ Adductor SD
- ☐ Mixed Abductor and Adductor
- ☐ Tremor only
- ☐ Abductor SD and Tremor
- ☐ Adductor SD and Tremor
- ☐ Abductor, and Adductor, and Tremor

Other (please specify), or "don't know"

4. How many years ago did you develop SD symptoms?

5. How many years did it take between the time you started having symptoms and the time when you were diagnosed by a medical professional as having SD?

6. Are you now receiving Botulinum Toxin injections (Botox) for your SD?

- ◯ Yes
- ◯ No

7. Have you had side effects of breathiness from Botox injections that significantly lessened the positive effects of the treatment?

- ◯ Yes
- ◯ No

8. When you were diagnosed, what severity level were you given in regards to your SD?

- ◯ Mild
- ◯ Moderate
- ◯ Severe
- ◯ Don't Know

9. Have you ever had surgery specifically for your SD diagnosis?

- Yes
- No

10. We are trying to learn more about how a voice problem can interfere with your day to day activities. Below, you will find a list of possible voice related problems. Please anser all questions based upon what your voice has been like over the past two weeks. There are no "right" or wrong answers. Considering both how severe the problem is when you get it, and how frequently it happens, please rate each item below on how "bad" it is (that is, the amount of each problem that you have). Use the following scale for rating the amount of the problem:

1=None, not a problem
2=A small amount
3=A moderate(medium) amount
4=A lot
5=Problem is as "bad as it can be"

	1	2	3	4	5
1.) I have trouble speaking loudly or being heard in noisy situations.	○	○	○	○	○
2.) I run out of air and need to take frequent breaths when talking.	○	○	○	○	○
3.) I sometimes do not know what will come out when I begin speaking.	○	○	○	○	○
4.) I am sometimes anxious or frustrated (because of my voice).	○	○	○	○	○
5.) I sometimes get depressed (because of my voice).	○	○	○	○	○
6.) I have trouble using the telephone (because of my voice).	○	○	○	○	○
7.) I have trouble doing my job or practicing my profession (because of my voice).	○	○	○	○	○
8.) I avoid going out socially (because of my voice).	○	○	○	○	○
9.) I have to repeat myself to be understood.	○	○	○	○	○
10.) I have become less outgoing (because of my voice).	○	○	○	○	○

Should you become upset after taking this survey and wish to speak to a professional counselor, please call Thomas Hofmann at 239-707-9127 or by e-mail at thofmann@hodges.edu. You may also find this contact information on the e-mail you received that invited you to participate in the study.

3. You have chosen not to participate in the survey

Thank you very much for your time and attention.

You may close this webpage to end contact with this website. Please click the "exit this survey" link at the top right hand corner of this page. Or, you may click the next button and click the close button on the following page.

4. Contact Information for the Researchers

Thank you for your time and attention.

If you have and questions or concerns about this survey, please contact Thomas Hofmann at 239- 707- 9127 or by e-mail at thofmann@hodges.edu. You should receive a response within 24 hours. Please click the "exit this survey" link at the top right of the page to close this page. Or, click next and then click close on the following page.

5. Thank you!

Thank you for your time!

Click the "exit this survey" link at the top right hand side of the page, or the "done" button below to close the browser.

Appendix B: INTRODUCTORY E-MAIL

(In Subject Heading) You are invited to participate in the "Spasmodic Dysphonia and Quality of Life" survey

You are invited to participate in a study of how quality of life is affected by spasmodic dysphonia (SD). This survey will take approximately 15 minutes to complete. The researchers hope to provide information to other researchers and professionals about how well people cope with SD and the challenges people with SD face in their lives.

You have received this e-mail through the cooperation of the National Spasmodic Dysphonia Association. However, please note that the National Spasmodic Dysphonia Association does not endorse or recommend participating in the study.

Please contact the lead researcher, Tom Hofmann if you have any questions about the survey. He can be reached by e-mail at thofmann@hodges.edu or by phone at 239-707-9127.

The link below will direct you to the survey. You will be asked to read some important information about the study, and then you will be asked to decide if you want to proceed. The survey is entirely voluntary.

Click this link to take the survey:

https://www.surveymonkey.com/s.aspx?sm=h4hDHuhns5PGCPTlBZ3m_2fA_3d_3d .

Appendix C: V-RQOL ALGORITHMS

.

V-RQOL General Scoring Algorithm:

100- [(raw score- # of items in domain or total)/(highest possible raw score- # of items)*100]

V-RQOL Total Score

100-[((Raw Score-10)/40)*100]

V-RQOL Physical Functioning Domain

100-[((Raw Score-6)/24)*100]

Raw Score= V-RQOL question scores 1+2+3+6+7+9

V-RQOL Social-Emotional Domain

100-[((Raw Score-4)/16)*100]

Raw Score= V-RQOL question scores 4+5+8+10

V-RQOL Questions

We are trying to learn more about how a voice problem can interfere with your day to
day activities. On this paper, you will find a list of possible voice-related problems. Please
answer all questions based upon what **your** voice has been like over the past **two weeks.**
There are no "right" or "wrong" answers.
Considering both how severe the problem is when you get it, and how frequently it
happens, please rate each item below on how "bad" it is (that is, the **amount** of each

problem that you have). Use the following scale for rating the amount of the problem:

1 = None, not a problem
2 = A small amount
3 = A moderate (medium) problem
4 = A lot
5 = Problem is as "bad as it can be"

1. I have trouble speaking loudly or being heard in noisy situations.
1 2 3 4 5

2. I run out of air and need to take frequent breaths when talking.
1 2 3 4 5

3. I sometimes do not know what will come out when I begin speaking.
1 2 3 4 5

4. I am sometimes anxious or frustrated (because of my voice).
1 2 3 4 5

5. I sometimes get depressed (because of my voice). 1 2 3 4 5

6. I have trouble using the telephone (because of my voice).
1 2 3 4 5

7. I have trouble doing my job or practicing my profession (because of my voice).
1 2 3 4 5

8. I avoid going out socially (because of my voice). 1 2 3 4 5

9. I have to repeat myself to be understood. 1 2 3 4 5

10. I have become less outgoing (because of my voice). 1 2 3 4 5

Appendix D: T-TEST SPSS OUTPUT

Comparison of ABSD and ADSD by V-RQOL Total Score

Group Statistics

	SDTYPE	N	Mean	Std. Deviation	Std. Error Mean
VRQOLTOT	1.00	41	43.7195	22.98180	3.58915
	2.00	86	44.2733	22.47504	2.42355

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
VRQOLTOT	Equal variances assumed	.003	.958	-.129	125	.898	-.55374	4.29642	-9.05690	7.94941
	Equal variances not assumed			-.128	77.236	.899	-.55374	4.33077	-9.17700	8.06951

Comparison of ABSD and ADSD by V-RQOL Physical Functioning Subscale

Group Statistics

	SDTYPE	N	Mean	Std. Deviation	Std. Error Mean
VRQOLPHY	1.00	41	41.4634	22.24296	3.47377
	2.00	86	43.4109	23.23390	2.50538

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
VRQOLPHY	Equal variances assumed	.195	.659	-.448	125	.655	-1.94744	4.35014	-10.55690	6.66202
	Equal variances not assumed			-.455	81.996	.651	-1.94744	4.28299	-10.46767	6.57279

Comparison of ABSD and ADSD by V-RQOL Social-Emotional Functioning Subscale

Group Statistics

	SDTYPE	N	Mean	Std. Deviation	Std. Error Mean
VVRQOLSE	1.00	41	47.1037	27.63806	4.31634
	2.00	86	45.5669	24.34559	2.62525

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
VVRQOLSE	Equal variances assumed	.896	.346	.318	125	.751	1.53680	4.82918	-8.02074	11.09434
	Equal variances not assumed			.304	70.526	.762	1.53680	5.05200	-8.53779	11.61138

Appendix E: REGRESSION ANALYSIS OUTPUT

Regression

[DataSet0] C:\Documents and Settings\Administrator\Desktop\Dissertation Data\Regression.sav

Descriptive Statistics

	Mean	Std. Deviation	N
VRQOLTOT	44.8551	23.97488	69
DURATION	11.0290	8.14026	69
AGE	51.0435	12.56446	69
SEVERITY	2.3623	.66357	69
SIDEEFFECT	1.2609	.44233	69
GENDER	1.2609	.44233	69

Correlations

		VRQOLTOT	DURATION	AGE	SEVERITY	SIDEEFFECT	GENDER
Pearson Correlation	VRQOLTOT	1.000	.212	.272	-.052	.031	.111
	DURATION	.212	1.000	.217	-.214	.124	-.166
	AGE	.272	.217	1.000	.240	.059	.265
	SEVERITY	-.052	-.214	.240	1.000	.024	.124
	SIDEEFFECT	.031	.124	.059	.024	1.000	-.052
	GENDER	.111	-.166	.265	.124	-.052	1.000
Sig. (1-tailed)	VRQOLTOT	.	.040	.012	.335	.399	.182
	DURATION	.040	.	.036	.038	.154	.087
	AGE	.012	.036	.	.024	.316	.014
	SEVERITY	.335	.038	.024	.	.423	.155
	SIDEEFFECT	.399	.154	.316	.423	.	.335
	GENDER	.182	.087	.014	.155	.335	.
N	VRQOLTOT	69	69	69	69	69	69
	DURATION	69	69	69	69	69	69
	AGE	69	69	69	69	69	69
	SEVERITY	69	69	69	69	69	69
	SIDEEFFECT	69	69	69	69	69	69
	GENDER	69	69	69	69	69	69

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	AGE	.	Forward (Criterion: Probability-of-F-to-enter <= .050)

a. Dependent Variable: VRQOLTOT

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Du Wa
					R Square Change	F Change	df1	df2	Sig. F Change	
1	.272[a]	.074	.060	23.24037	.074	5.366	1	67	.024	

a. Predictors: (Constant), AGE

b. Dependent Variable: VRQOLTOT

ANOVA[b]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	2898.345	1	2898.345	5.366	.024[a]
	Residual	36187.706	67	540.115		
	Total	39086.051	68			

a. Predictors: (Constant), AGE

b. Dependent Variable: VRQOLTOT

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	5% Confidence Interval for B	
		B	Std. Error	Beta			Lower Bound	Upper Bound
1	(Constant)	18.332	11.786		1.555	.125	-5.193	41.858
	AGE	.520	.224	.272	2.316	.024	.072	.967

a. Dependent Variable: VRQOLTOT

Appendix F: T-TEST RESULTS FOR MIXED SD V. ABSD/ADSD ANALYSIS

All Mixed SD v. Pure ABSD Plus ABSD

Group Statistics

	ABDMIALL	N	Mean	Std. Deviation	Std. Error Mean
VRQOLALL	1.00	157	43.1051	24.11644	1.92470
	2.00	73	35.8219	18.66674	2.18478

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confid Interval of Differenc Lower	U
VRQOLALL	Equal variances assumed	5.582	.019	2.281	228	.023	7.28318	3.19281	.99198	13.5
	Equal variances not assumed			2.501	177.719	.013	7.28318	2.91165	1.53732	13.0

Mixed v. Pure ABSD plus ADSD without Botox

Group Statistics

	ABDMIXNOBO	N	Mean	Std. Deviation	Std. Error Mean
VRQOLNOBO	1.00	97	43.7371	24.81212	2.51929
	2.00	29	39.6552	17.40695	3.23239

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference Lower	Upper
VRQOLNOBO	Equal variances assumed	5.415	.022	.826	124	.410	4.08194	4.94102	-5.69772	13.86160
	Equal variances not assumed			.996	65.319	.323	4.08194	4.09819	-4.10195	12.26583

Mixed v. Pure ABSD plus ADSD with Botox

Group Statistics

	ABDMIXBO	N	Mean	Std. Deviation	Std. Error Mean
VRQOLBO	1.00	103	45.1456	22.89368	2.25578
	2.00	41	34.6341	19.01941	2.97033

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
VRQOLBO	Equal variance assumed	1.194	.276	2.603	142	.010	10.51148	4.03884	2.52746	18.49551
	Equal variance not assumed			2.818	87.970	.006	10.51148	3.72980	3.09925	17.92372

ABSD Pure v. ADSD Pure

Group Statistics

	ABADBOT	N	Mean	Std. Deviation	Std. Error Mean
VRQOLBOT	1.00	33	46.0606	23.42733	4.07818
	2.00	70	44.7143	22.79613	2.72466

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
VRQOLBO	Equal variance assumed	.083	.774	.277	101	.782	1.34632	4.85627	-8.28721	10.97985
	Equal variance not assumed			.275	61.281	.785	1.34632	4.90462	-8.46016	11.15280